An Evaluation of the Physician Orders for Life-Sustaining Treatment (POLST) Program

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ABSTRACT

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The number of elderly in the U.S. (i.e., individuals age 65 years or older) is growing at a rapid rate.[1-4] While the current proportion of elderly persons living in U.S. is estimated to be little over 14%, it will soon reach up to 20% in next 10 years.[5,6] In addition, it is anticipated that the elderly population will soon outnumber the younger generations, for the first time in U.S. history.[2]

With the rapid shift we are witnessing in the U.S. population, the World Health Organization (WHO) informs that the leading cause of death in U.S. has also shifted: from infections to chronic illnesses.[7] The majority of elderly individuals will suffer from at least one chronic illness, and many will live longer than ever, with complex multiple healthcare needs.[8-11] The demands for specialized end of life (EoL) care among frail elderly will continue to rise,[12,13] and it is among the top research priorities to identify best practices in EoL care and understand how best to facilitate patient-centered care in healthcare settings.

In order to increase awareness in the importance of quality care provided to those who are near EoL, the Institute of Medicine (IOM; now the National Academy of Medicine) recommended a nation-wide implementation of an advance care planning tool, the POLST (Physician Orders for Life-Sustaining Treatment).[14,15] Designed specifically for frail individuals living with serious illnesses,[16] the POLST program is used to elicit care preferences and deliver goal-concordant care. Making patients' specific care wishes actionable and transferrable, it aims to preserve one's autonomy, and to allow them to die with dignity.[17-20] This dissertation aims to

evaluate the POLST program, from its effectiveness, dissemination, to outcomes associated with its maturity status.

The first chapter provides background information on the aging population the importance of advance care planning among frail elderly persons. The POLST program is introduced and I lay out the three research aims and the significance of each topic. Chapter 2 contains a systematic review of scientific evidence on the concordance between documented care wishes and actual care delivered to the POLST users. It explains specific care interventions that yielded high concordant care, as well as ones that had mixed results. In chapter 3, an environmental scan of a state-specific POLST program across all U.S. states and Washington D.C. is presented; the scan examined maturity status, specific care options mentioned/ absent as well as descriptive statistics on the association between presence of infection/pain-related care options and the POLST program maturity status. In chapter 4, a quantitative analysis aimed at examining the impacts of the POLST program maturity status on a patient-level outcome (i.e., nursing home death) is presented. In it, multiple large datasets were used to generate a representative sample of the U.S. nursing home population. I then applied multivariate logistic regression modeling to estimate associations. Lastly, chapter 5 synthesizes the findings of this dissertation as well as strengths and limitations. It then shares recommendations for policy, clinical practice and future research.

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Chapter 1: Introduction

Chapter one consists of background information regarding the growing aging population and advance care planning. After discussing shortcomings of current advance care planning tools, the Physician Orders for Life-Sustaining Treatment (POLST) paradigm program is introduced. The current status of end-of-life care provided in long-term care settings is also described. The three research aims, the significance of each topic, the conceptual underpinnings, and organization of dissertation is explained.

Background

Aging Population

The average human life expectancy is increasing and this is a global phenomenon.[21,22] According to the World Health Organization (WHO), human life expectancy has increased from 64 years to 70 years, between the years of 2000 and 2016.[23] This is thought to be the *fastest growth* observed by far, potentially bringing multiple challenges in provision of healthcare, especially for those who are now living longer, with multiple health issues.[24] In the U.S. alone, the average life expectancy is reported to be higher than the global average (i.e., reaching up to 80 years), reflecting a rapid increase in the number of U.S. elderly (defined age of 65 years and older) persons.[25] With this unprecedented growth, it is projected that there will be an important demographic shift in the U.S.; that is, in next 15 years the elderly population will for the first time in U.S. history outnumber those who are 18 years and under.[26] Behind this fast-paced growth in the number of elderly persons stands two major events: the influx of aging baby boomers, and continued advances made in medical technologies.

The baby boomer generation first began turning age 65 in 2011, and this will continue for the next decade. By 2029, all baby boomers will be in the elderly group, constituting over 20% of total U.S. population.[19] Frailty, defined as the consequence of accumulated age-related defects in physiological symptoms, is thought to be among the most commonly encountered health issues this generation will face, as consequences of population living longer with advanced illnesses and/or multiple co-morbidities.[27]

Advances made in medical technologies have also contributed to the longer-than-ever human life expectancies. Innovations in biomedicine made an early detection of an illnesses possible, offering more curative treatment options, yielding a decline in overall mortality rate.[28,29] However, vast improvements in innovative medical interventions and technologies have

also inadvertently placed a heavy emphasis on *cure* of illnesses, rather than the *care* of individuals. It is not uncommon to witness terminally ill patients receiving highly aggressive and often futile treatments, especially when the patients' End-of-Life (EoL) care preferences and wishes are unknown.[30,31]

End-of-Life (EoL) Care and Advance Care Planning (ACP)

EoL care is a term used to describe the physical, psychological supports and medical care provided to an individual during the time surrounding one's death.[32] It aims to relieve sufferings while improving quality of remaining life of an individual living with life-limiting, or terminal illness.[33] Ideally, quality EoL care should reflect dying patient's own values, beliefs and goals while respecting his/her autonomy in medical care decisions.[34,35] One of the most critical elements in the planning and the delivery of quality EoL care is in the awareness and a shared understanding of patient's specific care preferences.[36] Without such information, medical interventions delivered at EoL were found to be more aggressive, geared toward the life-sustaining purposes, and more likely to cause protracted death by default.[37-40]

Advance Care Planning (ACP) is a process of discussing EoL care preferences between a patient and care providers, and formulate a future medical care plan.[40,41] It can inform and empower patients of their rights to have their care wishes respected, even when the patient becomes unable to verbalize his/her own choices.[33] Researchers have found positive associations between ACP and the quality of life in dying patients, and their family members. Specifically, ACP discussions have been linked with an increased concordance between treatments preferred and received at EoL, and decreased episodes of anxiety or depression reported among surviving relatives.[35,40]

Living wills and the health care proxy are the two most frequently used legal documents (i.e., advance directives; ADs), widely known as the cornerstones of ACP.[42] Living wills contain

written EoL care wishes, while health care proxy allows a dying individual to appoint a surrogate, who will make medical care decisions when the patient becomes incapacitated to make further choices.[43-45]

Shortcomings of Advance Directives (ADs)

It was in the mid-1960s when ADs were first introduced to the public. Developed by a human rights attorney, ADs were the first attempt in constructing a legal system that can help preserve the autonomy of incompetent medical patients.[46,47] Soon after, the U.S. congress passed the Patient Self-Determination Act, which became a pivotal event in raising awareness of ADs among general population.[48,49] Through the Patient Self-Determination Act, all U.S. health care institutions (e.g., Hospitals, Nursing Homes and Homecare Agencies) receiving Medicare/ Medicaid reimbursement were federally mandated to **a**) inquire about the presence of ADs in all adult patients, and to **b**) inform patients' rights to formulate ADs for future care, if one has not already done so.[48,49]

Nearly six decades after the birth of ADs, scientific evidence on the impacts of ADs (specifically, the roles it played in EoL care delivery) accumulated and the findings were mixed.[50,51] While there were benefits associated with the use of ADs (i.e., improved care satisfaction),[35,52] many researchers have also raised growing concerns on the limited use of ADs.[44,45,53,54] In an earlier study, published in 1993, researchers found that the actual proportion of individuals who completed ADs were low; ranging between 20 and 30 percent.[48,55-57] In the most recent studies, where researchers reviewed healthcare records from 2009 to 2016, similar findings were reported; completion rates were between 18 and 36 percent.[55,58,59]

Moreover, other shortcomings of ADs were identified, which include: use of ambiguous legal/ medical terms (e.g., *reasonable expectation* of recovery, or *minimally conscious*

condition); lack of transferability between care settings (e.g., hospitals to nursing homes); difficulty locating ADs under medical crisis, which led to unwanted care received; and limited scientific evidence supporting the effectiveness of ADs among frail individuals suffering from chronic, progressive cognitive illnesses (e.g., dementia).[44,45,54,60-65] Low completion rate and a limited body of scientific evidence that ADs can enhance goal-concordant EoL care among vulnerable population motivated efforts to seek an alternate ACP tool that can potentially close the existing gap between EoL care preferred and care being delivered.[45,55,62]

Physician Orders for Life-Sustaining Treatment (POLST) Program as a New ACP tool

In early 1990s, a group of medical experts in Oregon convened to discuss a concern that the EoL care preferences of individuals living with frailty and/or serious illnesses were not consistently honored.[66,67] With increasing scientific evidence showing low completion rate of ADs among frail individuals failing to ensure goal concordant care at EoL, a voluntary interdisciplinary task force (consisting of nurses, doctors and lawmakers) was formed to develop strategies to overcome such limitations.[68] An initial version of a newly invented tool from this taskforce was called a *Medical Treatment Coversheet*.[69] This was a single-page assessment of patient preferences for: resuscitation; level of medical services desired; antibiotics use; and artificial/ fluids and nutrition. After a successful completion of pilot studies in Oregon, this form was deemed feasible for the use within healthcare settings (i.e., clinical setting, and long-term care settings).[67] After some minor revisions were made, this tool was re-named as *Physician Orders for Life-Sustaining Treatment* (POLST) and disseminated state-wide.[70] By 2004, more than half of Oregon's healthcare settings such as hospital and NHs implemented the POLST program and POLST forms were used as a standard component of ACP.[71]

With a success of the POLST program witnessed in Oregon and a growing body of scientific evidence showing effectiveness of POLST use,[72-75] interests to adopt POLST program in other parts of U.S. have also increased. To meet the needs and provide a framework for a state-specific implementation and dissemination of POLST, a group of experts from different states (i.e., Oregon, New York, Pennsylvania) formed a committee called the National POLST Program Task Force.[18] Its members provided an on-going assistance with the program development, and acted as facilitators in the implementation of POLST programs in various states.[18,67] Over the next decade, nearly 90% of U.S. states (n = 45) have either officially developed, or were actively developing POLST programs for their states.[71]

There were a few characteristics and strategies that separated the POLST program from the existing ADs. For example, the POLST form was designed specifically for individuals living with serious illnesses or advanced diseases, for whom their care providers would not be surprised if a patient died within a year.[19] A close proximity between the time of EoL care planning (i.e., POLST form completion) and the actual time of death, offered an important opportunity to discuss and formulate a care plan, in light of patient's current medical condition(s). That is, rather than using a hypothetical situation as the basis of future care decisions as in most ADs, the POLST program introduced a *here-and-now* approach in EoL care planning.[65] In addition, the POLST form was designed to act as a vehicle that can facilitate important care discussions between a care provider and a dying patient.[72] Whenever the POLST form was used for ACP, it was mandated to document patient preferences for cardiopulmonary resuscitation, preferences for artificial nutrition administration and identify specific levels of care a dying patient wishes to receive (i.e., comfort-only, limited interventions only or full interventions for life-sustainment.[65] Discussing EoL care options and documenting care preferences on a POLST form with a medical

expert, rather than a legal expert (e.g., a lawyer), was an added advantage of the POLST form; when the questions arose during EoL conversation, medical experts were able to clarify or answer based on medical knowledge.[76]

Upon completion of a POLST form, patient's documented care wishes become a set of medical orders. By converting care wishes to a set of transferable and actionable medical orders, discordant care or unwanted interventions could be avoided. In some states (i.e., Oregon, West Virginia), POLST forms can be accessed through a state-wide electronic database, giving an opportunity for any healthcare providers to gain immediate access to patients' care wishes when needed across settings.[20,76] This was a particularly important step in ensuring patient-centered EoL care for elderly and frail individuals as they are at a higher risk of experiencing unexpected medical emergencies toward EoL.[77,78] First responders (e.g., emergency medical technicians and paramedics) arriving at the scene were able to access e-registry and identify the presence of POLST documentation, giving them a chance to deliver specific interventions that reflect patient's wishes.[79]

Nursing Home Use in Aging Population

Historically, institutional settings where services and supports are provided to help frail individuals and/or older adults with their daily activities were referred to as *long-term care* setting.[80] This is now used as an umbrella term, which includes: non-acute health care facilities such as adult day service center; home health agencies; residential care/ retirement communities; and nursing homes (NHs).[81] The latter also referred to as skilled nursing facilities, differ from other types of long term care facilities as its residents receive a continuous nursing care (i.e., 24-hour-a-day basis), either on a short term (e.g., post-acute rehabilitation) or long term basis.[82] With the increase in elderly population, demands for long term NH services is projected to rise.[82]

In recent studies on U.S. long term care services and its use, it was indicated that NHs had the largest shares of services users, nearly 1.5 million U.S. residents annually.[83,84] While 90% of these NH residents are aged 65 years and older, the oldest-old (i.e., age 85 years and over) represent more than half of all NH residents across the nation.[84] It is noteworthy that NHs are now at the forefront of delivering medical care to those who are vulnerable, frail, approaching EoL, and most often suffering from advanced/serious illnesses. A large body of scientific evidence shows that nearly 70% of all U.S. individuals living with an irreversible and progressive brain disorder (e.g., dementia, Alzheimer's disease), or a progressive neurodegenerative disease (e.g., Parkinson's disease) receive their care in NH settings, and even more likely so in the advanced stages of terminal illnesses.[85-87]

Nursing Homes and End of Life (EoL) Care

With a growing evidence that **a)** the NHs are important care settings for aging population, and **b)** demands for quality EoL care will continue to rise, it is critical to understand the current status of EoL care delivery in U.S. NH settings. Unfortunately, previous studies unanimously reported that the majority of NH residents are not receiving any formal EoL care (i.e., hospice or palliative care), even when they were eligible for receiving such services, based on their illness trajectories or limited life-expectancies.[88] Although it is well established that physical and psychological burdens increase drastically as one approaches EoL, the quality of care provided to the dying patients in NHs still remain sub-optimal.[85,89,90] In fact, it has been reported that a high number of NH residents were subjected to inappropriate EoL care practices and patterns; especially in their final months of life. Such findings were supported by poorly managed physical symptoms reported in the last month of life, frequent care transfers from NH to acute care facilities (e.g., emergency departments, intensive care units), which were deemed unnecessary and burdensome.[91-93]

To address a growing concern of sub-optimal EoL care, and to raise awareness on importance of symptom management near the EoL, the Institute of Medicine (now called National Academy of Medicine) released a set of recommendations for the care of individuals approaching death.[94] In these recommendations, palliative care was described as a highly effective care model, which helps to achieve the highest possible quality of life for individuals who are living with serious illnesses.[94] With emphasis on an urgent need for an ACP tool that is communication-based and patient-centered, these recommendations included a call for the nation-wide implementation of POLST programs in hopes of shifting the paradigm in U.S. EoL care system.[95]

Infections at the End-of-Life (EoL)

Along with physical sufferings, infections are among the most commonly encountered health complications at EoL.[96] Decreased immune functions, comorbidities and functional impairments such as urinary incontinence contribute to increased risk of infection among elderly NH residents.[97] Infection management in NH settings can be particularly challenging as this population tends to exhibit atypical and/ or non-classical signs and symptoms.[98,99] Studies show that up to 30% of elderly persons harboring serious infections remain afebrile.[98] Instead, non-specific changes such as failure to thrive, confusions or falls have been reported as signs of infections.[98] Combined with the fact that not all NHs are equipped with advanced technologies for early detection of infections, or have adequate resources readily available (e.g., in-house infection preventionist) for prompt consultations, high mortality and morbidity from infections are commonly observed.[100,101]

Infections at EoL remain as the primary reason for burdensome care transfers between NHs and hospitals.[91,102-104] Approximately 25% of all dying patients will experience recurrent

hospital transfers within days of their deaths.[77,105,106] Although scientific evidence supporting antibiotics use at EoL and health benefits in dying patients is lacking, care transfers due to infections are most commonly seen toward the EoL.[97] Frequent disruptions in continuity of care, repeated exposures to invasive procedures, increased risk of iatrogenic complications (i.e., pressure ulcers, confusions, functional declines) or nosocomial infections pose multiple serious health threats to the quality of life among already-frail NH residents.[107,108]

Significance

Gaps in knowledge

Although previously published studies have examined the effectiveness of the POLST programs, in terms of congruence between EoL wishes documented and honored, they were limited to a single institutional setting (e.g., hospice), [49,50] or a single state (e.g. Oregon).[72,73,109] The overall rate of congruence measured on a national level, across all different healthcare settings (i.e. hospice, hospital, nursing homes and community) is critical information, and yet has not been studied.

The national POLST paradigm task force mandates that all POLST forms include elements that can elicit patient preferences for: cardiopulmonary resuscitation; artificial nutrition; and specific level of care (i.e., comfort only, limited care or life-sustaining care).[110] Other than aforementioned elements, each state is allowed to include any EoL-relevant care options on a POLST form. A comprehensive examination of different types of care options presented in all POLST forms across the nation has never been conducted. A recent study of the POLST program and variations in POLST forms have only identified whether the mandated elements were present or absent.[111] Moreover, POLST forms from developing or non-conforming status were excluded from their review. Breadth and depth of EoL care options captured in all available POLST forms remain as a gap in knowledge.

Furthermore, there is a need for examining whether a state-wide implementation of POLST program is associated with individual level outcomes. And if so, identify whether differences in individual level outcomes differ based on the level of POLST maturity status (i.e., Mature, Endorsed, Developing and Non-conforming; highest to lowest). Previous research work informed that when a well-structured care system is introduced to NHs, diffusion of new knowledge produces changes in practices and cultures within organizations. For example, when the specialized EoL care team or hospice program was introduced a NH, significant improvements in the rate of EoL hospitalizations,[112,113] and the pain managements were noted throughout all NH residents (i.e., in both EoL care recipients and non-recipients).[114,115] Little research has examined the state POLST program, and maturity-status associated outcomes in its residents. The third aim of this dissertation study fills in the gap through investigating differences in the POLST maturity status across the nation and associated outcome observed in residents. For frail elderly NH residents at EoL, an important outcome to assess for the quality of care received at EoL is a place of death,[116-120] as hospitalization,[92,121-124] death at intensive care units and frequent transfers between care settings are known to be burdensome, contradict EoL care wishes, and cause discomfort needlessly.[92,117,118]

Conceptual framework

The conceptual framework guiding this dissertation is a modified Gelberg-Andersen Behavioral Model for Vulnerable Populations. (Shown in **Figure 1.**) This is a revised version of an original model, Andersen Behavioral Model, which is widely recognized as one of the most comprehensive conceptual frameworks in the analysis of healthcare utilization and access to care. [125-127]

The original version of the model was first introduced in 1960s in Andersen's dissertation work, as a result of his earlier exposure to a national healthcare survey data to guide researchers

studying healthcare utilization. Discovery of large disparities in people's access and utilization of healthcare services led him to develop the framework.[128] In it, Andersen explains that the use of health services is a function of three determinant factors; predisposition to use services [*predisposition*], enabling or impeding factors for service usage [*enabling*] and the need for the care [*need*].[129] Although the original model underwent numerous revisions to reflect evolving nature of research interests and changes in health care industry, the fundamental determinant factors (i.e., predisposition, enabling and need factors) remained unchanged.[125,126] Andersen's behavioral model for health services use is well-suited for this dissertation as it examines both contextual and individual factors that are associated with individual's health behaviors and outcomes.

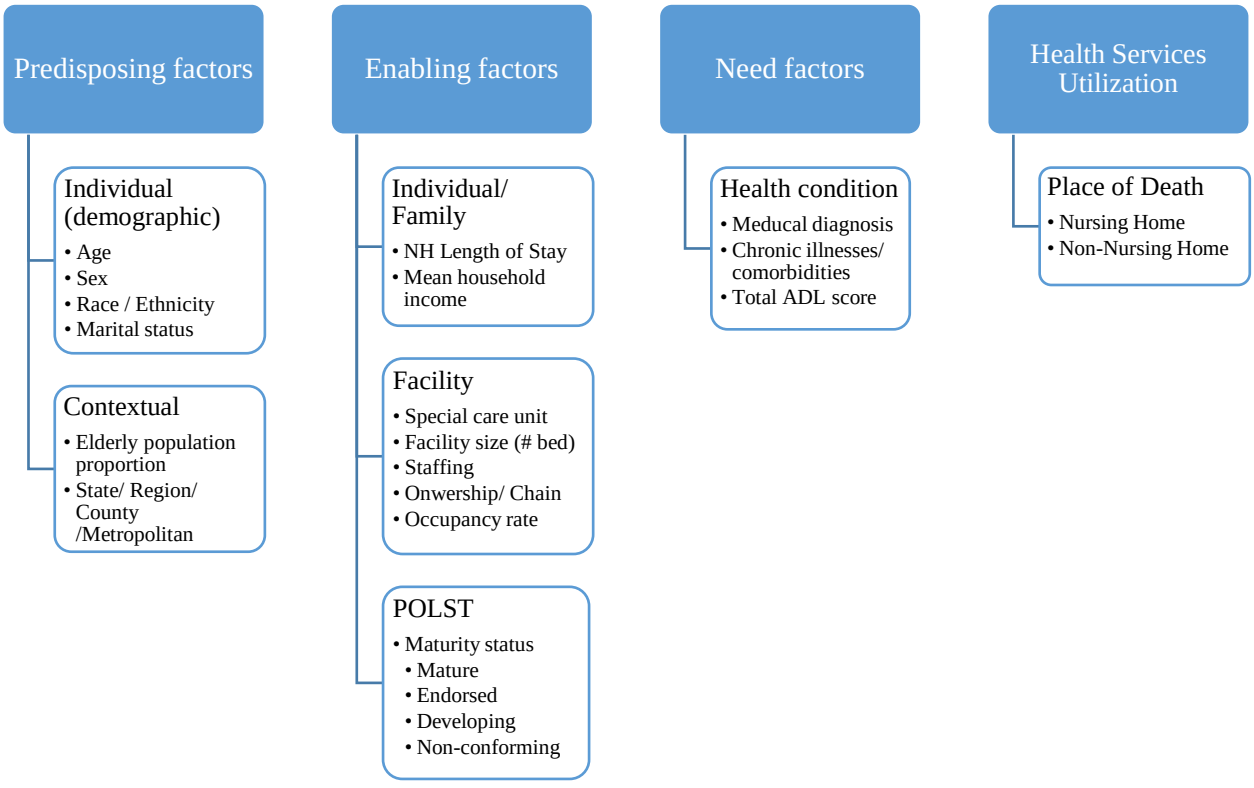

Figure 1. Gelbert-Andersen's The Behavioral Model for Vulnerable Populations

Predisposing factors

Predisposing factors are variables that existed prior to the onset of illness. It can be characteristics observed from an individual, or environment or surroundings (e.g., contextual). Although these variables are not directly responsible for either the presence or the absence of an outcome, individuals with certain characteristics are more likely to utilize health services.[130] For example, previous studies identified that certain individual characteristics are predictive of increased health services utilization; being older, married, and of a female gender has found to be positively associated with both access to, and cost of care.[131-133]

As depicted in **Figure 1**, demographic characteristics (age, sex) and social structures (marital status, ethnicity) are included under predisposing factors. Contextual predisposing factors include sociodemographic characteristics of a community. The proportion of elderly population living in a county and metropolitan/urban status are two examples of contextual predisposing variables.

Enabling factors

Enabling factors include resources available from family, or community. Mean household income (financial resources) is one of a few examples that can either enable, or impede health services use.[134] Community-based resources, such as available medical facilities within area, and NH-level characteristics (e.g., ownership type, chain membership status, and occupancy rates) can also influence the outcomes of service utilization. Previous studies identified that certain NH characteristics (e.g., availability of hospice program) were associated with increased use of health services.[112,135,136]

Other important variables under enabling factors include information pertinent to geographical locations (e.g., state, region, or county characteristics).[137] Through previous

research, it is known that the variations observed across different areas can play major roles in the rate of health services use including differences in number of hospitalizations or length of stay.[138-141] For instance, Temkin-Geener and colleagues reported significant differences in location of death, and quality of care provided for dying patients between NH facilities located in either rural or urban areas.[141] Crouch and colleagues have also noted significant geographic differences (i.e., rurality) associated with health services utilization and Medicare spending in the last six months of life in elderly patients.

The POLST program characteristics (i.e., maturity status and the total number of years since the state obtained developing status) will be included under the enabling factors. The differences observed among state-specific POLST programs are the focus of all three studies. The possible associations between POLST characteristics and individual-level health services utilization/ outcomes will be explored in the third aim of this dissertation.

Need factors

Need factors include health conditions of an individual that is professionally evaluated, or self-reported/ perceived that are associated with healthcare utilization. It also includes individual's functional abilities/ restrictions (e.g., activity of daily living) as well as physical and mental health status.[142-144] In a recent study, Li and colleagues reported that the presence of chronic illnesses (e.g., stroke, diabetes, heart disease) were associated with increased healthcare utilizations; visits to physician's office (both in/out patients settings), and the rate of hospitalizations.[145] In the same study, it was also emphasized that the higher healthcare utilization was observed among the group who reported problems with their self-perceived health.[145]

Health Services Utilization

Andersen's behavioral model is widely used in health science research, where researchers examined why and how we utilize health services. Previous studies indicate that there are different types of factors that can influence outcome (e.g., health services use), depending on the population of interest, health conditions or health services being studied.[146] Individual or socio-structural characteristics can predispose an individual's likelihood of seeking services, while enabling play important roles in frequencies (e.g., routine visits) or modes of health services use (i.e., routine office or emergency room visits as needed). Lastly, different health care needs (e.g., medical conditions) can also be considered to explain, and predict likelihood of future use of healthcare services. In studies 1, and 3, different modes of health services use will be discussed. Specifically, different types of care services utilized (e.g., antibiotic treatments, or artificial nutrition) will be explored in the first study, while utilization of NH (versus other settings) at the time of death will be examined in the third study of this dissertation.

Dissertation Aims

Study 1: Synthesize the evidence on the congruency between Physician Orders for Life-Sustaining treatment (POLST) documentation and subsequent care delivered to End-of-Life (EoL) for U.S. residents.

A systematic review of literature was conducted to examine whether POLST users' documented care wishes and treatment preferences were honored at EoL.

Study 2: Examine current status of POLST program implementation across U.S. and identify state variations in how infection and physical symptom management options are captured on state POLST forms.

An environmental scan was conducted to identify status of POLST implementation across U.S. settings, and then to examine treatment options mentioned on regional POLST forms.

Study 3: Controlling for other contextual and individual characteristics, examine impacts of POLST maturity status on the place of death (i.e., Nursing Home death) among elderly individuals residing in U.S. nursing homes.

Hypothesis: Controlling for other contextual and individual characteristics, the higher maturity status is positively associated with NH reported as the place of death among long-term residents.

Primary data collected during our environmental scan was linked with: NH resident level data using the Minimum Data Set 3.0 and Master Beneficiary Summary File; facility level data using Certification and Survey Provider Enhanced Reports; and county level data using Area Health Resource File to examine the place of death of the NH residents across the nation.

Potential Contributions

This research work contains comprehensive findings of the POLST program use and the associated outcomes in the national, state, facility, and individual-level. It carries multiple potentials to contribute to the body of health science research, especially in the issues surrounding advance care planning of frail and vulnerable population. The literature review generated the most up-to-date knowledge on the overall rate of congruency between preferred,

and actual delivery of EoL care interventions. It offered new, and important perspectives on both strengths and weaknesses that the state-specific POLST forms may have, evidenced by high, or low rate of congruence reported in our findings. In addition, this review can serve as an evidence-based guidance should future modifications and revisions in POLST composition be called for.

The findings from our environmental scan informed how infection management, and symptom management-related options were captured in all available POLST forms.[71] It was the first study to offer a comprehensive look at similarities, and differences between state-specific POLST forms that are currently in use. Primary data collected through this work has potential to be served as important state-level variables in the future studies involving the POLST program. When merged with other national-level large dataset (e.g., MDS) the potential contributions to the body of science will be even greater.

Examination of impact the POLST maturity status have on U.S. NH residents' place of death identified an important association between the state participation of the POLST program, and individual-level outcome. Place of death is frequently studied quality indicator for EoL care,[116,118] as death occurring in hospitals among frail elderly are linked with increased physical burden and diminished quality of life. Our findings have potential to influence state leaders and law makers to encourage implementation of well-structured ACP programs in U.S. states and continue to seek ways to enhance EoL care delivery system for all residents living with advanced illnesses.

Lastly, our findings generated from all three studies carry potential to enhance quality of life, and EoL care journeys for individuals living with any types of physical illnesses, regardless of their stages of illness trajectories. This work will bring awareness on the importance of

advance care planning resonates dying patient's specific care goals and remind encourages provision of high-quality medical care throughout all spectrums of life that every single individual deserves. It will become a solid foundational scientific knowledge that it is patient's basic right to retain autonomy and die with dignity.

Chapter 2: Congruence between End-of-Life Care Preferences using Physician Orders for Life-Sustaining Treatment (POLST) documentation and subsequent care delivered: A systematic review

The following chapter is a systematic review examining congruence between End-of-Life (EoL) care preferences documented using Physician Orders for Life-Sustaining Treatment (POLST) forms, and the subsequent medical care delivered to dying patients. This review followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement, and provided systematically, and critically appraised scientific evidence on the overall congruence rate of POLST sections: *CPR* documentation and resuscitation attempted, *hospital transfer*, *utilization of antibiotics*, *feeding tube* and *IV fluids use* at EoL.

Note: This chapter has been submitted for publication, and is currently under review for *BMC Journal of Palliative Medicine*

Abstract

Background

Physician Orders for Life-Sustaining Treatments (POLST) paradigm is an advance care planning program that is designed to facilitate End-of-Life care discussions between a medical provider and a terminally ill patient living with advanced illnesses. With an increased utilization of the POLST program in various healthcare settings and continued dissemination across the nation, it is important to examine scientific evidence on the congruence between care preferences documented on POLST form and subsequent medical care delivered.

Methods

PubMed, Cochrane Library, Embase, and CINAHL databases were searched. Eligible articles were: written in English, conducted in U.S., used quantitative research methods and published in a peer reviewed journal. Two researchers independently reviewed eligibility of articles, extracted relevant data, and assessed study quality. The New Castle Ottawa instrument was used to assess the quality of evidence The PRISMA guideline was followed.

Results

A total of 8 studies met eligibility criteria. Four studies were retrospective cohort design, 2 were prospective, and the rest cross sectional. All studies used chart review methods; one study included interviews. In total, 19,504 POLST forms were compared with medical records. Congruence between CPR documentation and resuscitation attempted or delivered varied (range 57% to 100%.) Preferences for hospital transfers were honored 90% of the time. Among those who opted no antibiotics, incongruent cases were found in 32% of forms. Wishes for limited antibiotics use at EoL were congruent with care delivered in over 90% of times. Use of feeding tube and IV fluids at EoL were congruent with written wishes in nearly 95% of cases. Quality of evidence was good in 6 and fair in 2 studies.

Conclusions

Resuscitation preferences documented on POLST forms were universally respected. Use of feeding tube or IV fluids at EoL showed mixed results. Additional research is recommended to identify congruence between POLST documentation and care delivered among patients who experienced multiple care transitions or have moved across state near the time of death.

Keywords: POLST, End-of-Life, Advance Care Planning, Advance Directives, Palliative care

Introduction

In 2014, the Institute of Medicine (now the National Academy of Medicine) released a consensus report, *Dying in America,* which raised an awareness on the importance of providing high quality end-of-life (EoL) care for those who are near death. In this report, appropriate EoL care was described as a vehicle that enhances quality of life for those who are near death, and as an essential factor to a more sustainable care system.[15] One of the conclusions was that there was a need for further state-wide adoption and active implementation of the patient-centered and communication-based advance care planning program, most commonly known as Physician Orders for Life-Sustaining Treatment (POLST).[15]

POLST was developed in early 1990s.[65] It is a portable advanced care planning order set that facilitates EoL care discussions between a medical provider and a patient, with the goal of increasing the likelihood of EoL care delivery that aligns with patient's values, beliefs, and goals of care. Although other advance care planning tools (i.e., living wills or health care proxy) exist, the POLST developers took a unique and enhanced approach. First, POLST was designed specifically for those who suffer from life-limiting illnesses and have a life expectancy of less than a year. Second, a completion of, or any revisions of POLST documentation require a treating practitioner's involvement and the signature to be valid. This was to reinforce that EoL care discussions and subsequent decisions should be guided by a medical provider who can clarify ambiguous medical terms, answer any questions, and to provide insights on implications of certain treatments that a patient is requesting or refusing. Lastly, it was designed to be an *actionable* and a *transferable* medical order, rather than a legal document. That is, the patient's care preferences documented on POLST becomes a set of medical orders [*actionable*] and it travels with a patient, regardless of medical care settings [*transferable*].

In Oregon, where POLST was developed, forms are electronically secured onto an e-registry unless patient chooses to opt out. In theory, in emergencies, any health care providers (including first responders at the scene) can access the e-registry and identify patient's EoL care wishes. Considering a complex and unpredictable illness trajectory at EoL, and a high utilization of emergency services among patients near death, state-wide implementation of the e-registry strengthened the way clinicians identify and honor dying patients' written EoL care wishes.

As of July 2018, 46 U.S. states and District of Columbia have developed state-specific POLST programs or are currently in the process of program development.[16] Moreover, research evidence showing positive impacts of POLST use (decreased care transfer at EoL and prevention of unnecessary medical interventions) continued to accumulate. [147-150]

Authors of a published review of the POLST program examined 7 states (i.e., Oregon, Wisconsin, New York, California, North Carolina, Washington and West Virginia) and identified impact of POLST use in hospitals, hospices and nursing homes. The authors found that the POLST is a widely used care planning tool, receiving increased attention in clinical care settings. The authors also emphasized the need to evaluate the concordance between care preferences documented on POLST forms and treatments given to dying patients.[110]

In EoL care delivery, where patient-centered care is a priority, examining concordant rate between care requested and intervention delivered is an integral part in understanding and planning high quality EoL care. However, published evidence on the concordance in POLST documentation and EoL care delivery has not been synthesized in a systematic review. The objective of this review is to examine the published evidence on the congruency between EoL care preferences documented on a POLST form and the subsequent medical intervention(s) delivered.

Methods

This systematic review followed the guideline of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).[151] Articles were eligible for inclusion if the authors examined the congruency between documented care wishes on a POLST form and subsequent care delivered to the patient. Other eligibility criteria also included studies that were written in the English, conducted in U.S., used quantitative methods, and published in a peer reviewed journal. Studies were excluded if the authors examined: the patient and/or family satisfaction on POLST form use and/or care delivered; the health care providers' perspectives on the ease of POLST use; the legal or ethical issues surrounding advance directives; the effects of advanced care planning tools other than POLST (i.e., living wills, advance directives); or, the quality of POLST form completion, editorials and qualitative studies were also excluded.

Information Sources

The search for literature was conducted using four electronic databases: PubMed, Cochrane Library, Embase, and Cumulative Index of Nursing and Allied Health Literature (CINAHL). A manual search of the reference lists to screen additional articles for eligibility was also conducted.

Search

The search was conducted in the Spring of 2018, after a consult with a library informationist. A comprehensive search methodology was developed, using free-text words and Medical Subject Headings (MeSH). Search terms included the following keywords: "Physician Orders for Life-Sustaining Treatment", "POLST", "MOLST", "Advance Directive Adherence/Utilization", "Advance Care Planning", "Treatment Adherence and Compliance", "End of Life Care Planning", "Consistency", "Congruence" and "Concordance". Searches were not restricted by patient age, publication date, or care settings where POLST user resided (i.e.,

home, nursing home, acute care facility, or hospice). This was to allow a comprehensive screening of articles that may meet our eligibility criteria.

Study selection

After removing duplicate articles, titles and abstracts were screened to identify those that were relevant to the aim of this review. When the article was deemed relevant, full text was obtained for further screening applying the inclusion and exclusion criteria.

Data collection process

A standardized data abstraction tool was developed, which included the following information about the manuscript demographics: title, first author, and year published. Data audited on the study itself included: research design, region, setting, sample size, population of interest, and POLST section(s) examined for congruency (i.e., Cardiopulmonary Resuscitation (CPR), hospital transfer/ Intensive Care Unit (ICU) admission, preferred care setting / location of death, antibiotics, feeding and IV fluids and overall congruency). An evidence base table was developed to present the study characteristics and findings.

To assess bias and quality of studies, we used the Newcastle-Ottawa Assessment Scale (NOS). The NOS is a validated quality assessment tool that is widely used for assessing quality of observational studies.[152-154] The NOS examines three domains of a study quality: selection (4 items), comparability (1 item), and outcome (3 items). When the highest criteria are met, 1 star per numbered item is awarded for both the selection and outcome domains. For the compatibility domain, the maximum number of stars awarded is 2, with the maximum possible stars awarded per study being 9. The NOS scores were converted into a trichotomous measure using the Agency for Health Research and Quality guidelines as follows: Good quality includes 3 or 4 stars in the selection domain, 1 or 2 stars in the comparability domain and 2 or 3 stars in the outcome domain; Fair quality includes 2 stars in the selection domain, 1 or 2 stars in the

comparability domain and 2 or 3 stars in the outcome domain; Poor quality includes 0 or 1 star in the selection domain or 0 stars in the comparability domain or 0 or 1 stars in the outcome domain.[155] Two researchers (AT and JS) independently assessed each eligible article, and then met to discuss findings. A senior researcher (PS) was consulted to resolve any discrepancies.

Results

Figure 2 shows a PRISMA study flow diagram. In total, we identified 605 articles. After removal of 15 duplicates, 590 articles were screened for eligibility. Sixty-four articles were deemed relevant and proceeded to full-text review. After applying the predetermined inclusion and exclusion criteria 56 articles were excluded leaving 8 studies.

Overview of Included Studies

Table 1 summarizes the eight research studies audited. Five studies were conducted in Oregon, one study in Wisconsin, and two studies included two or more states. Care settings were varied: 4 studies were conducted in community settings, 3 studies in nursing homes, and 1 in a hospice setting. Six retrospective cohort studies and 2 cross sectional studies were included. Studies were published between the years of 1998 and 2014. Chart review was the most frequently used research methods (n = 7) while one study included chart review and in-person interviews.[79]

The combined study sample size was 19,504 patients who completed POLST documentation with the majority coming from 1 study having over 17,000 patients. The majority of studies (n = 7) examined whether performing or not performing CPR was congruent with patient's written wishes indicated.[72,156-161] Two studies had CPR congruence as the only outcome of interest, while 5 studies also examined other outcomes: hospital transfer (n = 1), antibiotics use, IV fluids (n = 1), hospital transfer, tube feeding (n = 1), antibiotics, tube feeding (n = 1) and

hospital transfer, antibiotics (n = 1).[72,156-158,160] Two studies also examined an overall congruence by totaling the rate of congruence obtained from different sections.[142,144]

Study Findings

Cardiopulmonary Resuscitation

In 4 of the 7 studies, in which researchers examined documented Do-Not-Resuscitate orders, none of the patients from a hospice or nursing homes received unwanted CPR.[72,157,158,160] Three studies showed varying degrees of congruence. In one nursing home study with 54 patients whom indicated their CPR preferences, researchers found that the provision of CPR was congruent in 49 cases (90.7%); incongruent cases (n = 5) were due to three patients who received CPR against POLST documentation, and for 2 patients whom did not received CPR although POLST documentation indicated that they wished to receive it.[156] Two studies examined the rate of congruence in CPR among patients residing at home, for whom emergency medical service calls were made.[159,161] In one study, 4 of 7 patients (57%) received CPR that was congruent with POLST documentation.[159] Of remaining 3 cases, 1 patient (14.2%) was dead at the scene, receiving no medical interventions, and 2 (28.6%) received CPR until emergency personnel was able to retrieve data by calling an e-registry hotline. In the other study, CPR was congruent with patient wishes in 27 cases (84%).[161] Researchers noted that no patients with a documented preference for CPR had resuscitation efforts erroneously stopped by emergency service personnel.

Hospital Transfer / Intensive Care Unit (ICU) Admission

Tolle and colleagues prospectively followed 180 nursing home residents who opted for hospital transfer only when comfort measures failed.[72] After a year, 24 residents (13.3%) experienced hospitalizations. Rationales for hospital transfers were congruent with EoL care wishes documented on POLST in 22 cases (85%). In the 2 incongruent cases (15%), hospital

transfers were to extend life, rather than for comfort enhancement. Of those who were admitted to ICU setting, or received any treatments provided in ICU settings (e.g., intubation).

Other researchers compared 157 forms obtained to medical records from the last 30 days of life. All documentation indicated that the hospital transfers made for patients were only for comfort purposes. Of 15 total hospitalizations identified, the majority of hospital transfers (13 out of 15, 86.7%) were to control pain or sufferings.

Preferred Care Settings / Location of Death

Patient's documented preferred care setting (e.g., current residence or hospital/ ICU) were compared with the actual location of death in one study.[162] Most (n = 11,836) patients' written wishes were to remain in their current settings, unless their pain and sufferings could not be controlled. Some (n = 4,787) indicated wishes to be transferred to hospital for medical treatments at EoL, but avoid ICU admission or stays, and 1,153 patients requested transfers to hospital including ICU settings to receive life-prolonging medical interventions. Of those patients who wished to remain in their current settings, 758 patients (6.4%) died in hospitals or emergency rooms. The majority (n = 10,464, 88.4%) patients died in their own residence or at out-of-hospital settings, representing a high congruence between preferred care setting, and the location of death. Of those who wished to be transferred to hospitals, but avoid ICU stays, 1,073 (22.4%) deaths occurred in hospital settings. Nearly half of patients (44.2%) who indicated their wishes to be transferred to hospitals, including ICU, for any medical interventions had the hospital setting listed as their place of death.

Antibiotics

Congruency between antibiotics use at EoL and POLST documentation were examined in three studies.[156,158,160] Hickman and colleagues examined 709 POLST documents, which contained patient's written wishes for use of antibiotics at EoL. Of 28 patients who opted for *no*

antibiotics,[158] 9 patients (32.1%) received antibiotics treatments against their written wishes. Two discordant cases (22.2%) occurred when a family member revoked the original POLST order; rationales were not provided in the remaining 7 cases (77.8%). Of the 227 POLST forms with *limited antibiotics* preference indicated (i.e., patient wishes to receive antibiotics only for symptom relief), 60 patients met treatment criteria. Fifty patients (83.3%) received congruent care, where antibiotics were administered to enhance their comfort.

In another study,[160] researchers examined 52 forms from patients who opted to receive antibiotics. Thirty patients met treatment criteria (i.e. developed infections at EoL), and all received congruent interventions. A high rate of congruency between the use of antibiotics and documentation was also evident in another study.[156] When researchers identified total 28 forms with documented preferences for antibiotics use, 24 patients (85.7%) received antibiotics.

Feeding and Intravenous (IV) fluids

When preferences for feeding tube were compared with medical charts from the last 2 weeks of life, researchers found that the feeding tubes were implemented in 32 patients (94.4%).[156] In one discordant case, the patient (2.9%) received a feeding tube when it was not indicated; another discordant (2.9%) case involved an incident where the patient opted for feeding tube, but did not receive one. In the same study, researchers also examined 38 POLST forms which had preferences written for the use of IV fluids at EoL. IV fluids were administered in 32 cases (84%).

Other researchers examined 678 forms of deceased nursing home residents.[158] Most (n = 417, 61.5%) indicated wishes to not receive feeding tube at EoL. Chart review revealed that almost all (n = 416, 99.8%) received concordant care. Of the 193 deceased nursing home residents who requested to receive feeding tube at EoL, but only for *defined trial period*, the researchers found 5 patients (2.6%) had a feeding tube in place for longer than 30 days,

indicating a long-term usage. Furthermore, 4 of these patients (80%) died with the feeding tube in place.

When Hammes and colleagues reviewed 268 POLST documentation from one community setting,[160] only 4 POLST forms indicated *long-term feeding tube* use. Two participants (50%) did not meet treatment indications (i.e., needing tube feeding to meet caloric requirements to sustain life) and another two (50%) received feeding tube at EoL.

Overall Congruency

After examining different POLST sections (i.e., CPR section, antibiotics section) and congruence with each care delivered per section requested, researchers in three studies further computed an overall congruency between documentation and all applicable medical interventions withheld/ provided.[156-158] In one study, the researchers initially found 52 potential discordant cases (20.4%) from 255 POLST documentation and medical chart reviews.[157] However, further review of these discordant cases revealed two important factors. First, most discordant cases involved family member or surrogate's request to withhold medical interventions (e.g., CPR). And such decisions to override patient's POLST wishes were most often occurred after they were informed by medical providers that the patient would not likely to survive even if treatment [requested on POLST form] were delivered.[157] By conducting further review of discordant cases, researchers were able to conclude that only 2 out of 255 cases (4%) showed incongruent care.

The overall congruence reported in another study was significantly lower.[156] After comparing types of EoL care interventions delivered to the patient with the corresponding sections of total 54 POLST forms (i.e., CPR, transfer, antibiotics, artificially administered nutrition and artificially administer fluids section) only 21 cases (39%) showed that all written EoL care wishes were honored. Twenty-eight cases (51%) showed that only about half of

POLST sections were congruent with actual care delivered at EoL. Three cases (5.6%) were congruent in fewer than half of POLST sections examined, whereas two cases (3.7%) showed discordant care in all POLST sections examined.

Quality of included articles

Table 3 provides a summary of the methodological quality assessment of all included studies. The quality scores ranged from minimum 7 stars to maximum of 9, with half of the included studies scoring 8 stars. All included studies scored the highest possible in outcomes domain, that is 3 stars. All studies clearly stated means of outcome assessment, length of follow up, and adequate rate (i.e., 80% or higher) of participants followed up. Five studies (62.5%) had 2 stars awarded in comparability domain, which assesses whether study participants were controlled for cofounders. Three studies did not control study groups for potential confounding factors other than age, sex or marital status. Lowest scores were found in the selection domain. Only three studies (37.5%) scored 4 stars while rest scored 3. Although all included studies had representative study sample, there were no description or inclusion of non-exposed cohort (that is, those who did not have POLST forms) in 5 studies.

Discussion

To the best of our knowledge, this is the first systematic review that examined the congruence between POLST documentation and subsequent medical care delivered to patients at EoL. Our review synthesizes the evidence on the congruence rate between 1) specific POLST section and care delivered, as well as 2) overall congruence of POLST documentation and EoL care received.

Most of the included studies were retrospective cohort studies that were conducted in medical facilities (e.g., nursing homes). Preferences for receipt of resuscitation in the event of

cardiac arrest and the actual delivery of or withheld of resuscitation efforts was the most commonly studied intervention. It is also where the highest congruence rates were observed.

There were several incongruent cases noted in the delivery of EoL care interventions, namely, hospital transfer, antibiotics use, and feeding tube use. Most commonly reported reason for unwanted hospital transfers, or the use of antibiotics among dying patients were new onset of infections. Previous studies on the health status of nursing home residents revealed that infections are, in fact, the most commonly encountered health problems among elderly population.[163-165] Also, it is one of the most common factors that causes unplanned changes in one's EoL care processes.[166] Combined with the fact that not all nursing homes are adequately equipped to provide screening of, or management of infections that are prevalent in EoL, it appears to be a challenging task to bring immediate changes, or measurable outcomes in this aspect of EoL care.[167] However, continued efforts in infection surveillance, antibiotic stewardship and in-depth understanding of resident's EoL care goals are one of few strategies that can be implemented to minimize over-utilization of potentially harmful treatments.

Overall congruence between preferred use of feeding tube and actual care delivered revealed another area that needs improvement. Researchers pointed that incongruent cases in feeding tube use were most commonly seen among those who opted to have feeding tubes only *defined trial period.* Some patients had feeding tube in place for longer than 30 days, raising concern for what constitutes as a *trial period*, and some even died with feeding tube in place. Researchers called for the need for clarification of the term *defined trial period* as it has never been defined by the National POLST Program Task Force (NPPTF) organization. Although it is difficult to conclude that incongruent cases in feeding tube use were solely due to lack of consensus on definition, such finding raised am important issue that languages used in medical

forms, especially in advance care planning document, should avoid any terms that can be misinterpreted or misunderstood.[168]

One of notable study findings was the evidence of high congruence for a preferred route of medication administration. Among those who expressed EoL care preferences to receive antibiotics, but only via oral routes, all (100%) study participants received care that was congruent with their written wishes. This signifies a high specificity that can be achieved through POLST forms. This finding resonates with previous research work, which noted an effectiveness of POLST forms in guiding EoL care.[17] Meier and Beresford explained that POLST provides a quick and clear guidance in EoL care, through highly specific care preference documentation for common interventions used in EoL journey.[17] When examining concordance between POLST documentation and subsequent care delivered to patients, it is important to understand that some discordant cases may arise from issues that are related to POLST form itself (structural issues) or differences in familiarity of POLST program among general population. While POLST is gaining increase attention across the nation, NPPTF allows each U.S. state to develop a state-specific POLST program and operate it independently.[168,169] This, in turn, leaves a room for inherent differences to arise in type of EoL care addressed and the option one can choose from. For example, Wisconsin POLST form offers four different options under tube feeding preferences (i.e., no feeding tube, defining period usage, long-term use or determine the use when needed) while West Virginia only offers two (i.e., no feeding tube, or long-term feeding tube use).

Type of EoL care option captured on state forms also differ significantly. For example, antibiotics options are no longer being assessed through POLST form in the state of Oregon. In 2012, Oregon's POLST coalition made an executive decision to remove antibiotics preference

section from its POLST form, after nearly 20 years after POLST program was developed.[170] Such decision was due to a new research findings. That is, Hickman and colleagues found that antibiotics section on POLST forms had little impact on the actual usage of antibiotics between two groups (patients who opted for antibiotics at EoL and patients who opted for no antibiotics at EoL). In this retrospective cohort study, the actual use of antibiotics at EoL were similar between two groups, regardless of written wishes indicated on antibiotics section; 32.1% and 30.4% respectively.[158] In addition, lack of research evidence that antibiotics use at EoL enhances survival outcomes or comfort for those who are near death supported Oregon's decision to remove antibiotics use section in its entirety.

Each state participating in POLST program has different levels of program designation, classified as maturity status. From lowest to highest status, a state POLST program can move from *developing*, *endorsed*, and *mature* status when it meets certain milestones or key criteria that NPPTF requires.[16,171] When the program first begins a state-wide dissemination of POLST, it obtains a *developing* status and then move toward endorsed when the state consensus is met for a single POLST form for a state-wide, and then to *mature* status when POLST becomes a part of standard of care for elderly and frail patients and is used as an advance care planning tool in more than half of all medical facilities (e.g., nursing homes, hospitals, hospice care settings) within its state.[171] Depending on the maturity status of the POLST program, public awareness on POLST program itself, and how it can be utilized to tailor one's EoL care may vary significantly. For example, in an area where POLST program is used in the majority of healthcare settings, medical providers may be more familiar with the fact that POLST forms should be re-visited when patient status improves or declines further, and patients be given many opportunities to reflect any changes in care preferences during EoL care journey. Unfortunately, different levels

of public or provider awareness and competency on how POLST can be utilized to tailor one's EoL care remains unstudied, which could explain discordant cases observed in included studies.

Making EoL care decision is a challenging process. It can also be emotionally draining for those who are faced with or involved in decision processes. A well-informed advance care planning requires a utilization of a guiding tool that facilitates care discussions, while presenting treatment options that are relevant to EoL care. It should also be systematically monitored for continued quality improvement and be closely examined for outcomes it brings to its target population. This systematic review synthesized published evidence on the congruence between POLST documentation and subsequent care delivered at EoL, and provided comprehensive resource for healthcare providers, health science researchers or policy makers who are seeking scientific evidence on POLST use and impact it brings. It is clear that gathering additional scientific evidence on the use of POLST across different care settings or regions will help advance future EoL care practices.

Limitations

There are number of limitations that are worth mentioning. First, although we developed search strategy with the help of library informationist, it is possible that our search strategy may have not identified all relevant research articles on this topic. Second, while we limited our inclusion criteria to research articles published on peer reviewed journals, potentially important and relevant findings that addressed our research question could have been existed in grey literatures, and/or unpublished articles. That is, publication bias may be present with studies not finding concordance not being published. Third, we found that several authors on included research articles had affiliations with NPPTF; some served their roles as consultants or board members. In addition, one of authors in the included study appeared as co-author in two other included studies.

Another significant limitation of this systematic review is that five of included studies were conducted in the state of Oregon, and two other multi-state studies included Oregon as one of their geographic study locations. Although this could be considered as a limitation, POLST was first developed, introduced, and disseminated in Oregon. Needless to say, as a birthplace of POLST program itself, the most number of resources and data are available from Oregon.

Conclusion

Based on our findings, it is clear that POLST is an effective advance care planning tool that can be used to discuss, document, and to deliver EoL care that reflects patient's care preferences. Provision of resuscitation at the time of cardiac arrest or time of death was universally respected, while there were mixed results in the use of feeding tube or IV fluids use at EoL.

Additional research is recommended to identify congruence between documented care wishes and actual care delivered among patients who experienced multiple care transitions or have moved across state near the time of death. Further studies should also compare congruence between POLST documentation and care delivered between groups of patients who may suffer from different medical conditions. Empirical studies are needed to ascertain the comprehensiveness of POLST items in capturing relevant and important EoL care interventions. There is a need to conduct prospective observational studies within various patient care settings, across all age span.

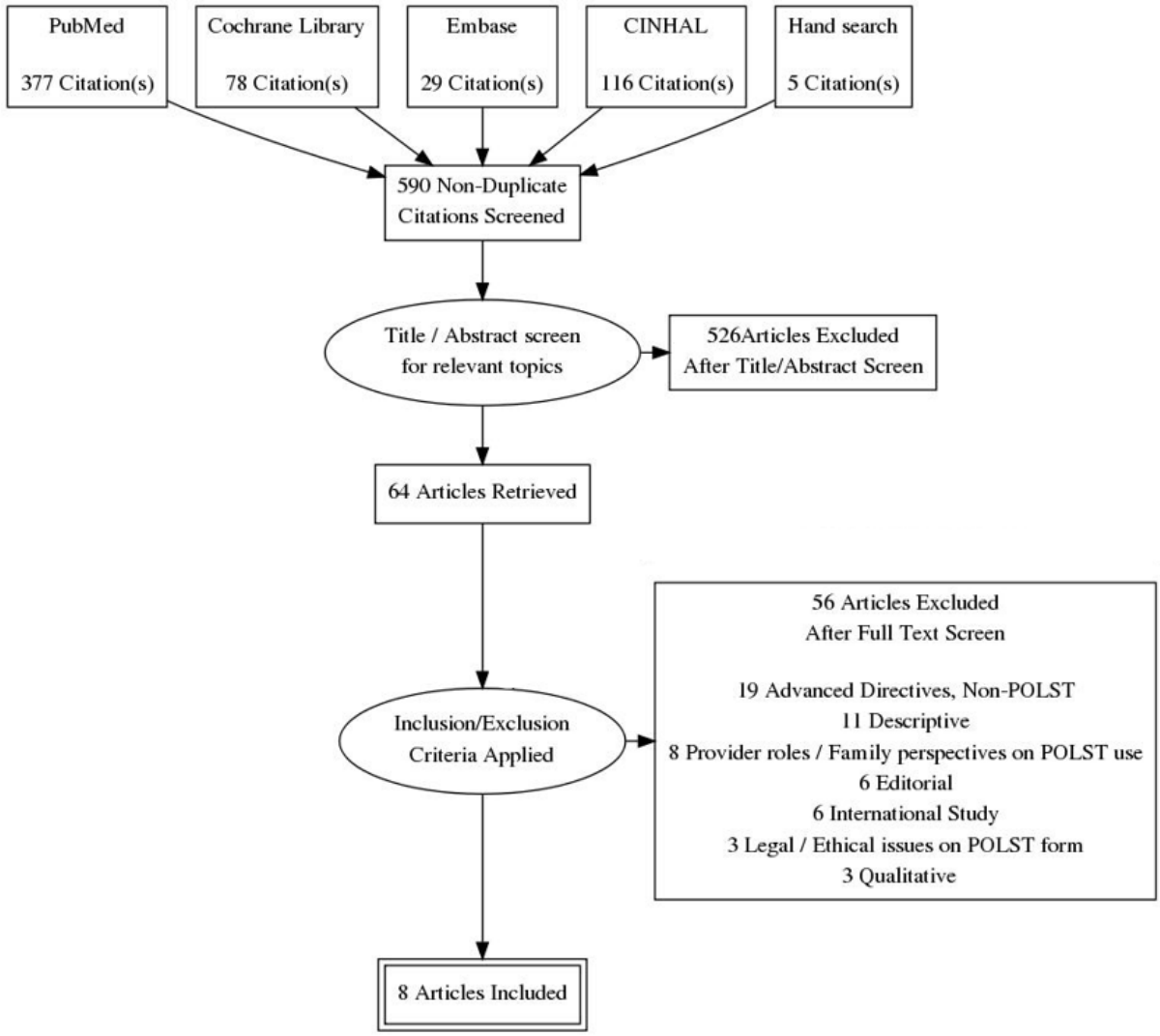

Figure 2. PRISMA flow diagram for article selection

Table 1. Evidence Base Table of Audited Studies

Author (Year)	POLST Section included	Study Design / Method used	State	Setting	Sample size (n)	Population of interest	Findings
Tolle, et al., 1998	CPR Hospital transfer / ICU admission	Prospective / Chart review	OR	Nursing Homes	180	Residents who had a POLST recording DNR designation, and opted for a transfer only if comfort measures failed	None of study participants received unwanted CPR. Among 26 participants (13%) who were hospitalized during the study period, no one received ICU care, or ventilator support. In 85% of hospitalizations, patients were transferred because the nursing home could not control suffering; in four cases (15% of hospitalizations), the transfer was to extend life. None of hospitalized participants received CPR in the hospital, and orders to focus on comfort-oriented care were universally respected.
Lee, et al., 2000	CPR IV fluids Antibiotics Overall congruence	Prospective / Chart review	OR	Nursing Homes	54	Residents who died in year 1997, and had POLST forms	Overall, 21 participants (39%) had POLST instructions followed in all applicable categories of care. 28 participants (51%) received care that matched POLST at least half of categories of care. For 3 participants, care consistent was fewer than half of relevant categories. For 2 participants, care provided was not compliant with POLST. CPR category was consistent with POLST instructions in 49 cases (91%). The medical treatment that subjects received was at the level of medical intervention ordered in 25 cases (46%), at less invasive level in 18 cases (33%) and at a more invasive level in 11 cases (20%). Among those who opted to receive artificially administered nutrition and IV fluids had their wishes honored 94% of the time. Antibiotic administration was in concordance with POLST documentation 86%.
Hickman, et al., 2009	CPR Hospital transfer/ ICU admission Tube feeding	Retrospective / Chart review	OR WI WV	Hospice	256	Residents with POLST forms	Preferences for treatment limitations were respected in 98% of cases and no one received unwanted CPR, intubation, ICU, or feeding tubes. Eight (3%) treatment deviations identified of 255 subjects. 3 patients received less aggressive treatment, 5 received overtreatment.
Hickman, et al., 2011	CPR Antibiotics Tube feeding	Retrospective/ Chart	OR WI WV	Nursing Homes	741	Residents who had a POLST form	Of 299 deceased residents with DNR order, none received unwanted CPR, 100% of residents received treatment consistent with their orders. 74.3% (26/35) of treatment provided to residents with orders for “comfort only” were consistent with the goal of enhancing comfort. 98.3% of treatment provided were consistent with the “limited additional” intervention order. The overall consistency rate between treatment provided and orders about medical intervention was 91.1% The consistency between antibiotics use and POLST documentation was

	Overall congruence						92.9%. For feeding tube preference and use, consistency rate was 63.6%. Overall consistency between all treatments provided and POLST orders was 94%
Schmidt, et al., 2013	CPR	Cross sectional/ interview & chart review	OR	Community	34	EMT personnel, patients (or surrogates) for whom the calls were made	Chart review revealed there were two subjects who received CPR and medical interventions until the POLST forms were identified through POLST registry, after which they were terminated to follow POLST orders for DNR. Three cases matched the recorded wishes and one subject requested a transport, overriding POLST form. During patient/surrogate interview, 10 out of 11 (91%) of interviewees believed that written POLST care wishes of the patients were honored.
Hammes, et al., 2012	CPR Hospital transfer / ICU admission Antibiotics	Retrospective / Chart, Death Certificates review	WI	Community	255	Residents who died between Sept 2007 – March 2008, and had a POLST form	None of the 255 decedents with a dated POLST form were resuscitated in the last 30 days of life. 5 decedents who opted to receive full treatment option had hospitalization, ICU stay and intubation. None of 157 decedents who documented Comfort-care only under Section B. were intubated or received care in ICU setting. Of the 4 decedents who had orders for long-term feeding tube use, two received feeding tubes; the other did not because the treatment was not indicated. Antibiotic use was consistent with POLST orders; 20 decedents received antibiotic treatments to enhance comfort, and 10 decedents with no IV/IM antibiotics received antibiotics which were administered orally.
Fromme, et al., 2014	Preferred care settings/ location of death	Cross-sectional / Chart, Death Certificates review	OR	Community	17,902	Residents who died of natural causes from 2010-2011, had a POLST form	Striking difference in proportion of in-hospital death that was consistent with POLST orders. Of all subjects with POLST, only 6.4% with Comfort-only care (hospital transfer only to enhance comfort, with no ICU care) died in the hospital compared with 44.2% of those with orders for full treatment (transfer to hospital or ICU), and 34.2% for those with no POLST form. Overall, POLST users' wishes to avoid hospitalization were honored.
Richardson, et al 2014	CPR	Retrospective / Chart review	OR	Community	82	Residents with out-of-hospital Cardiac arrest, who had a POLST form	Of 50 subjects with DNR order, 11 subjects (22%) had resuscitation attempted by EMS personnel. By hospital admission, resuscitation efforts had been ceased or not attempted for 94%. Of 32 patients with a POLST form specifying attempt resuscitation, 27 (84%) had resuscitation attempted. Overall, concordance rate of patients with DNR orders having resuscitation efforts stopped before hospital admission was 94%.

CPR: cardiopulmonary resuscitation; DNR : do not resuscitate; ICU: intensive care unit; IV: intravenous; MIS: medical intervention section (i.e. comfort only, limited treatment, full treatment); EMS : emergency medical service; IM : intramuscular

Table 2. Methodological Assessment of Included studies Using the Newcastle-Ottawa Scale (NOS)

NOS items	Tolle, et al., 1998	Lee, et al., 2000	Hickman et al., 2009	Hickman et al., 2011	Schmidt, et al., 2012	Hammes, et al., 2012	Fromme, et al., 2014	Richardson, et al., 2014
Selection								
Representativeness	*	*	*	*	*	*	*	*
Selection of the non-exposed			*				*	*
Ascertainment of exposure	*	*	*	*	*	*	*	*
Change in outcome	*	*	*	*	*	*	*	*
Comparability								
Comparability	**	*	*	**	*	**	**	**
Outcome								
Assessment of outcome	*	*	*	*	*	*	*	*
Follow up	*	*	*	*	*	*	*	*
Adequacy of follow up	*	*	*	*	*	*	*	*
Total star awarded	8	7	8	8	7	8	9	9
Overall quality	*Good*	*Fair*	*Good*	*Good*	*Fair*	*Good*	*Good*	*Good*

" * " : meet NOS threshold

Note : Good quality: 3 or 4 stars (*) in selection domain AND 1 or 2 stars in comparability domain AND 2 or 3 stars in outcome domain; Fair quality: 2 stars in selection domain AND 1 or 2 stars in comparability domain AND 2 or 3 stars in outcome / exposure domain; Poor quality: 0 or 1 star in selection domain OR 0 or 1 stars in outcome / exposure domain

Chapter 3: Variations in Physician Order for Life-Sustaining Treatment (POLST) program across the nation: Environmental Scan

The following chapter is an environmental scan conducted to examine current status of POLST maturity status across the nation, and to examine similarities and differences in incorporation of infection, and symptom management options address on all available POLST forms.

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Abstract

Background

Physician Orders for Life-Sustaining Treatments (POLST) is an advance care planning tool that designed to document End-of-Life (EoL) care wishes of those living with limited life expectancies. Although positive impacts of POLST program has been studies, variations in state-specific POLST programs across the nation remains unknown.

Objective

Identify state variations in POLST forms and to determine if variations are associated with program maturity status.

Design

Environmental scan.

Measurements

Using national POLST website, state-specific POLST program characteristics were examined. With available sample POLST forms, EoL care options were abstracted.

Results

Of all 51 states (50 U.S. states and Washington, D.C examined), the majority (n=48, 98 %) were actively participating in POLST; 3 states (5.9%) had Mature status, 19 states and District of Columbia (39.2%) were Endorsed, 24 states Developing (47.1%), and 4 states (7.8%) non-Conforming. Forty-five states (88.2%) had forms available for review. Antibiotics and intravenous fluids options were identified in 32 (71.1%), and 33 (73.3%) POLST forms respectably. Hospital transfer and use of oxygen were mentioned in all forms. Use of respiratory devices (i.e., CPAP and BiPAP) were mentioned on 27 (60%) forms while ventilator or intubation use were mentioned in 36 POLST forms (80%). No associations were found between POLST maturity status and provision of treatment options.

Conclusions

Variations in integration of infection and symptom management options were identified. Further research is needed to determine if there are regional factors associated with provision of treatment options on POLST form and differences in actual rate of infection or symptoms reported.

Introduction

Advances in medical technologies, combined with an aging population, have resulted in an increased number of individuals living with complex health issues. Previous researchers found that the number of elderly Americans suffering from chronic illnesses and comorbidities has increased drastically.[9,172 65] Many of these people are at the end-of-life (EoL) and at risk for infection, which is often terminal but results in burdensome hospitalizations.[15,121] Despite wishes to remain at home and avoid aggressive treatments, many individuals die in acute care settings, including emergency rooms or intensive care units.[117,120,173] Delivering care that reflects individual's values is a priority of care at EoL.

Discussions eliciting patients' preferences for interventions at EoL are difficult. As many as 70% of individuals at the EoL lack the capacity to communicate their preferences due to the progressive and advanced nature of their illnesses (e.g., dementia or stroke).[174] Advance care planning, a process of documenting individual's preferences for medical care, is one way to understand individual's preferences in the face of incapacity. In U.S., Living wills are the most widely used advance care planning tool.[175] Since the passing of the Patient Self-Determination Act in 1990, which promoted the use of advance directives, public awareness on advance directives has increased; however, this has not translated into an increased proportion of individuals who actually complete advance directives.[176] Although it has been nearly 6 decades since advance directives were first introduced, the proportion of individuals completing advance directives remains low (i.e., less than 30% completion rate), and EoL care remains suboptimal.[45,177,178]

Recognizing shortcomings of conventional advance directives, and to fulfil the need for an alternative tool that can help honor a patient's EoL care wishes, a group of medical ethicists

from Oregon formulated a new advance care planning tool called the Medical Treatment Coversheet in 1991.[69] After validating the instrument and successfully completing pilot studies, it was renamed "Physicians Orders for Life-Sustaining Treatments (POLST)" and was released for use in Oregon in 1995. Similar instruments have been developed in other states, but there are some differences.

Although POLST and advance directives share similar aims, which are to document individual's EoL care wishes, they differ in important ways. Advance directives are designed for any adult age 18 years or older; POLST targets people who are suffering from advanced, progressive, illnesses and/or frailty, and living with limited life expectancy.[54,62] By targeting intended users with advanced illness and who are close to death, POLST offers the opportunity for dying patients to articulate their care preferences with the knowledge of their on-going medical conditions. In addition, medical interventions documented on POLST forms become a set of portable medical orders upon completion, which increase the likelihood that the patient's preferred treatment options will be honored across care settings.[158] The POLST paradigm was designed not only to preserve the autonomy of terminally ill individuals, but also to facilitate much needed EoL conversations between a dying patient and treating medical providers.

While the effectiveness of the POLST program and the positive impact it has had on EoL care is well-documented in previous studies, implementation of the POLST program has been driven by states, resulting in state-level variation in POLST content, timing, and rates of adoption, the consequences of which have not been addressed adequately.[179-181] Currently, the National POLST paradigm Task Force (NPPTF) supports implement and operation of state POLST programs, requiring only that the general tenets of POLST Form Usage Policy be followed (i.e., POLST must be a voluntary tool and be used within the intended population),

which has resulted in wide variation in POLST design and content across the country, [169,182,183] including EoL treatment options that are discussed and care preferences documented. A close examination of this variation is an important step in identifying best practices in POLST programs.

The NPPTF monitors and designates the "maturity" of state-specific POLST programs using 4 categories, each representing different stages of program development and implementation (see http://polst.org/programs-in-your-state/).[171]

Developing status indicates that the state coalitions have contacted NPPTF to develop a state-specific POLST program and are currently working toward the goal of implementing statewide POLST program. States with developing status can be at any stage of program development activities, ranging from a designing phase of POLST forms, to on-going regional pilot studies with POLST program.

Endorsed status is for the states where POLST programs have been implemented, and have met key criteria (i.e., presence of a single POLST form per state). Different issues relevant to the state-level POLST program (i.e., legal, regulatory, education, and quality improvement) must also be addressed.

Mature status is the highest level of POLST recognition. It is reserved for states where the POLST programs have been endorsed as a part of the standard of care. Mature status is obtained after NPPTF confirms that the POLST program is being used in more than 50% of all medical facilities (i.e., hospitals, nursing homes, and hospices).

Lastly, for POLST programs that are already developed, but failed to comply with requirements in either structural component of POLST forms, or how the programs are being

implemented within a state (e.g., voluntary), *non-conforming* status is assigned. This status indicates that the state's POLST program is not on a pathway to be endorsed by NPPTF.

The purposes of this research study were to: 1) identify state variations in how EoL treatment options were captured on POLST forms through environmental scan, and 2) determine if variation in EoL treatment options on the POLST forms was associated with the maturity status of the program. Environmental scan is a research method widely used in assessment of both internal and external environment of an organization, organizational practices, or health programs. It produces important insights on current trends and occurrences based on exciting resources and can assist with the development of evidence-based policies in future practices.

Methods

An environmental scan was conducted using the national POLST website (www.polst.org), states' Department of Health websites and by searching the internet to identify the most up-to-date information on POLST programs in all 50 U.S. states and the District of Columbia (hereby referred to as states). Data collection occurred between August 2017 and February 2018. When available, sample POLST forms were obtained using state POLST websites and/or by searching the World Wide Web.

A standardized data collection tool was developed (available upon request) after reviewing the national POLST website, published research articles describing the POLST program, and consultations with experts.[110] The following data were obtained: **a**) name of each state POLST program; **b**) POLST program maturity status; **c**) year POLST program began; **d**) year POLST program was endorsed or distinguished as mature (when applicable), and **e**) availability of a sample POLST form (Y/N). When the POLST program had a non-conforming maturity status, we further identified the reason (i.e., specific tenet it violated).

When a POLST form was available, we examined how EoL treatment management options were captured including: antibiotics use, intravenous (IV) fluids, hospital transfer, medication administration by any route, oxygen use, utilization of less-invasive respiratory devices (i.e., Bi-level Positive Airway Pressure (BiPAP) or Continuous Positive Airway Pressure (CPAP)) and invasive respiratory devices (i.e., ventilation/ intubation). Because aforementioned treatment options can be found in multiple different places in a POLST form (i.e., under Comfort Measures, Limited Treatment and Full Treatment and/or under a separate assessment section), for each treatment option we assessed **a)** the frequency the treatment option listed, and **b)** the location(s) where the treatment options were found on the form.

A double data collection process was performed; for every 5 states in which data were collected by the first data collector (AT), a second data collector (MA) randomly selected one state and independently extracted data. During the data collection period, all authors met weekly to discuss findings, review data collection progress and to clarify any discrepancies. Inter-rater agreement was calculated using the kappa statistic. Distributions and descriptive statistics were computed, and chi square tests were used to test for associations between POLST maturity status and treatment options.

Results

Data were collected from all 51 state POLST programs (i.e., 50 states and Washington, D.C.). The inter-rater agreement was excellent (Kappa = 0.77).[184]

Table 3 presents the characteristics of the programs. The distribution of state POLST program start years is presented in **Figure 3**. The first program began in 1991 (Oregon) and the most recent began in 2017 (Arkansas). Excluding three states that did not specify the start year (i.e., Marylnd, South Dakota and Wyoming), half (n = 24) of all state programs began between

the years of 1991 to 2008, and the rest in the years of 2009 to 2017. The maximum number of state programs that began in the same year were 6 programs, which occurred in year 2010, followed by 5 programs in year 2012.

Three states (i.e., California, Oregon and West Virginia, 5.88%) had mature status, 20 states (39.22%) were endorsed, 24 states (47.06%) were developing, and 4 states (7.84%) were non-conforming. Reasons for non-conforming included: missing a core elements (Massachusetts, Vermont), omitting limited-intervention section on the form (Nebraska) and mandating completion to certain patient population (Maryland).

The year that state's program obtained its endorsed status was identifiable for 23 states. Between years of 2004 and 2017, a total 20 states obtained, and maintained their endorsed status, while 3 states went on to obtain a higher (i.e., mature) status. An average time it took for a state program from the start year to the receipt of endorsed status was 6 years (SD = 4.09, median = 5). New Hamphire's POLST program took the longest time to transition from start to endorsed status, total 14 years, while Hawaii's POLST program took less than a year to move from start to endorsed status.

Of the three states that went on to obtain mature status, both Oregon and West Virginia's programs obtained mature status in 2013. Oregon maintained endorsed status for 13 years before it obtained mature status, and West Virginia maintained endorsed status for 3 years. California obtained mature status in 2016, after having endorsed status for 9 years. In average, it took 8 years (SD = 1) for a state POLST program to transition from endorsed to mature status; maximum 9 years, and minimum 7. An average of 14 years were lapsed between the year it started, and the year mature status was obtained.

There were several different names used. The majority (n = 18, 35.29%) used the name POLST, followed by POST (Physician Orders for Scope of Treatments) in 8 states (15.69%). Seven states (13.73%) used the name MOLST and 6 states (11.76%) used MOST with the "M" standing for Medical. Two programs (3.92%) were called TPOPP (Transportable Physician Orders for Patient Preferences) and another 9 states (17.65%) used state-specific names (e.g., AzMOST for Arizona, DMOST for Delaware, OkPOLST for Oklahoma, WyoPOLST for Wyoming). The program name for one state (i.e., South Dakota, 1.96%) was not specified.

Forty-five states had forms available for review. The 6 states that did not have a sample POLST forms were Alabama, Alaska, Nebraska, South Dakota, Wisconsin and Washington D.C,). All mature programs (n = 3) had a sample form available; 19 from endorsed programs, 20 from developing, and 3 forms from non-conforming programs.

Frequencies and specific locations for the EoL treatment options are presented in **Table 4**. Patient preferences for antibioitc therapies were assessed on 32 forms (71.11%); 2 out of 3 programs from mature status (66.67%), 14 out of 19 (73.68%) endorsed and developing, and 2 out of 3 (66.67%) non-conforming status. Most forms assessed antiobiotic preferences only once (n = 28, 62.22%); and, it was most frequently listed under the full treatment section (n = 15, 33.33%), followed by the comfort measures section (n = 13, 28.89%). There were 4 forms (8.89%) that contained antibiotics use under two different sections; these sections were comfort and limited section (n = 3) or limited and separate section (n = 1).

Preferences for IV fluids use at EoL were assessed on 33 forms (73.33%), which included all forms from mature programs (n = 3, 100%), more than half of forms from endorsed (n = 13, 68.42%) and developing status (n = 16, 80%) and 1 from non-conforming program. Similar to antibiotics use, preferences for IV fluids were mostly mentioned once per form (n = 28, 62.22%);

however, it was listed under the limited treatment section. Five forms (11.11%) assessed IV fluids use option twice per form, all under a limited and full treatment section.

Patient preferences for the hospital transfer at EoL were assessed in all forms (n = 45, 100%). Three quarters of state forms (n = 34) captured transfer option three times; under all medical intervention sections (i.e., comfort, limited and full treatment). When this option was mentioned twice (n = 5, 11.11%), they were all under a comfort and limited treatment section. When mentioned once (n = 4, 8.89%), all were located under a separate section.

All forms assessed patient preferences for medication administration by any route, as well as the options to receive oxygen for respiratory symptom relief. These preferences were all captured under the comfort measures section. All forms from mature and non-conforming status contained the option to use respiratory devices (i.e., BiPAP/CPAP and intubation/ventilation). Program maturity status was not related to the assessment of BiPAP/CPAP preferences, with this present 94.74 to 100% of the time. All forms that contained preferences for intubation and ventilation use (n = 41, 91.11%) mentioned this option only once and this weas mostly under full treamtent sections (80%), or under a separate section (11.11%).

Because there was no variation in three treatment options (i.e., transfer to hospital, medication by any route, oxygen) associations between maturity status and treatments options could only be compared to antibiotics use, IV fluids use, BiPAP/ CPAP, intubation/ventilation use. We did not find any significant associations between treatments mentioned and POLST maturity status (data not shown).

Discussion

This is the first comprehensive examination of how POLST forms vary across the nation. Variations in types, interventions, locations, or frequencies of options captured on forms could

be explained by the lack of consensus on specific EoL treatment care options that should be addressed. Maturity status of the program was not related to the variation in the forms.

Previous researchers largely focused on the use in clinical care settings (i.e., nursing homes), or lessons learned from implementing a program in a single state.[185-187] Recently, Hickman and Critser reported their findings on the national and state level variations in POLST programs.[181] However, their study aimed to identify whether the state forms were adherent to the national standards by identifying inclusion of specific sections (e.g., medical order) and exclusion of language that ia prohibited by NPPTF. These investigators only examined the sample POLST forms from endorsed or mature programs, excluding information from developing or non-conforming POLST programs from their final analysis.[181]

A large number of unnecessary and burdensome hospital transfers occur near EoL.[188] These transitions become a source of disconcordant care that increases both psychological and physical burdens for a dying patient. It is also closely related to the overutilization of aggressive treatments that may contradict a dying patient's EoL care wishes.[12,91] Many elderly individuals with advanced illness transferred to hospitals die within weeks of hospitalization.[122,123,189] While conventional advance directives do not assess individual's preference for hospitalization near death, all POLST forms we examined (n = 45, 100%) contained a hospital transfer option, at least once. Most forms contained hospital transfer under all three sections (i.e., comfort, limited and full treatment sections).

Decision-making surrounding antibiotics use at EoL is difficult parts. Due to ethical concerns, examining outcomes (e.g., quality of life) among dying patients with or without antibiotics use is not feasible through randomized control trials. As a result, the evidence is based on retrospective cohort designs, with no comparison groups.[190-193] Lack of guidelines, and the

absence of high-level scientific evidence on antibiotics use at EoL adds challenges to determining what is the best practice in the infection managements among elderly and frail individuals.[96,194]

Oregon, the birthplace of POLST program, included an antibiotics option on its form since the first time POLST was introduced. However, nearly a decade after the program's initiation, this section was remove after a review of research evidence found little difference in actual use of antibiotics regardless of written preferences.[158]

An aim of POLST is facilitate advance care planning that can enhance quality of life for those who are dying. By using a standardized national tool, one should be able to receive a care that is documented and desired, regardless of patient's physical location (e.g., care institution located in a different state). Even if the care transfer was made near the time of death, across states, POLST documentation should always be easily identifiable and patient wishes be respected. The variations we observed make interstate transfer of POLST orders unlikely.

Limitations

This environemntal scan was limited to EoL treatment options that were relevant to infection and/or symptom management. Discussing treatment options outside infection/ symptom management (such as tube feedings) were out of scope of this study. While we attempted to be comprehensive and current, not all forms were available. Our findings represent a cross-sectional view, and it does not provide causality. The forms used during data collection may have been revised, and/ or maturity status changed. Although it may be useful to report summary of changes that were made to states' POLST programs or forms since the completion of our data collection, Oregon is currently the only state where such changes are reported, on an ongoing basis.

Oregon has recently separated from NPPTF, due to differences in views for receipt of industry funding. [44] Although the national POLST website indicated that Oregon's POLST program was mature, this information has subsequently been removed.[70,152,170] Nevertheless, we classified Oregon's POLST program status as mature program throughout our data collection and analysis.

Directions for the future research

We highlighted a gap in knowledge in current status of POLST program implementation. Future research is recommended to identify how variations in EoL care options, particularly antibiotics preferences and other infection-related care options, addressed on advance care planning tools impact appropriate use of medication at EoL. Determining if EoL care wishes on POLST forms were honored for individuals who relocate to a different state, close to the time of death, is also needed.

This study yielded information that can inform policy makers, researchers and clinicians. Close monitoring of POLST program for its futher improvements, and disseminating new research findings on areas that can be improved will facilitate further success of POLST program. In addition, it will provide a platform for increased public awareness on the importance of formulating patient-centered EoL plan.

Table 3. State POLST Characteristics

State	POLST maturity status	Program name	POLST started (yr)	POLST endorsed (yr)	POLST matured (yr)	Reason for Non-Conforming status
Alabama*	Developing	TOPP	2004	N/A	N/A	
Alaska*	Developing	MOLST	2015	N/A	N/A	
Arizona	Developing	AzMOST	2012	N/A	N/A	
Arkansas	Developing	POLST	2017	N/A	N/A	
California	Mature	POLST	2007	2009	2016	
Colorado	Endorsed	MOST	2005	2011	N/A	
Connecticut	Developing	MOLST	2012	N/A	N/A	
Delaware	Developing	DMOST	2010	N/A	N/A	
Florida	Developing	POLST	2003	N/A	N/A	
Georgia	Endorsed	POLST	2012	2013	N/A	
Hawaii	Endorsed	POLST	2009	2009	N/A	
Idaho	Endorsed	POST	2007	2011	N/A	
Illinois	Developing	POLST	2010	N/A	N/A	
Indiana	Endorsed	POST	2013	2017	N/A	
Iowa	Endorsed	IPOST	2006	2015	N/A	
Kansas	Endorsed	TPOPP	2008	2016	N/A	
Kentucky	Developing	MOST	2010	N/A	N/A	
Louisiana	Endorsed	LaPOST	2011	2012	N/A	
Maine	Endorsed	POLST	2008	2015	N/A	
Maryland	Non-Conforming	MOLST	N/S	N/A	N/A	POLST form not voluntary
Massachusetts	Non-Conforming	MOLST	2010	N/A	N/A	Lacking limited intervention section
Michigan	Developing	POST	2011	N/A	N/A	
Minnesota	Developing	POLST	2009	N/A	N/A	
Mississippi	Developing	POST	2014	N/A	N/A	
Missouri	Endorsed	TPOPP	2008	2016	N/A	
Montana	Endorsed	POLST	2010	2011	N/A	
Nebraska*	Non-Conforming	POLST	2005	N/A	N/A	Lacking core elements of POLST form
Nevada	Developing	POLST	2009	N/A	N/A	
New Hampshire	Endorsed	POLST	2003	2017	N/A	
New Jersey	Developing	POLST	2011	N/A	N/A	
New Mexico	Developing	MOST	2012	N/A	N/A	
New York	Endorsed	MOLST	2003	2006	N/A	
North Carolina	Endorsed	MOST	2004	2008	N/A	
North Dakota	Developing	POLST	2010	N/A	N/A	
Ohio	Developing	MOLST	2006	N/A	N/A	
Oklahoma	Developing	OkPOLST	2007	N/A	N/A	
Oregon	Mature	POLST	1991	2004	2013	

State	POLST maturity status	Program name	POLST started (yr)	POLST endorsed (yr)	POLST matured (yr)	Reason for Non-Conforming status
Pennsylvania	Endorsed	PAPOLST	2000	2011	N/A	
Rhode Island	Developing	MOLST	2011	N/A	N/A	
South Carolina	Developing	POST	2012	N/A	N/A	
South Dakota*	Developing	N/S	N/S	N/A	N/A	
Tennessee	Endorsed	POST	2005	2009	N/A	
Texas	Developing	MOST	2013	N/A	N/A	
Utah	Endorsed	POLST	2002	2011	N/A	
Vermont	Non-Conforming	COLST	2005	N/A	N/A	Lacking core elements of POLST form
Virginia	Endorsed	POST	2006	2016	N/A	
Washington	Endorsed	POLST	2000	2005	N/A	
West Virginia	Mature	POST	2002	2005	2013	
Wisconsin*	Endorsed	POLST	1997	2008	N/A	
Wyoming	Developing	WyoPOLST	N/S	N/A	N/A	
Washington D.C.*	Developing	MOST	2015	N/A	N/A	

Note: *: POLST form not available for review; N/S: not specified; **AzMOST**: Arizona Medical Orders for Scope of Treatment; **COLST**: Clinician Orders for Life Sustaining Treatment; **DMOST**: Delaware Medical Orders for Scope of Treatment; **IPOST**: Iowa Physician Orders for Scope of Tretament**; LaPOST**: Louisiana Physician Orders for Scope of Treatment; **MOLST**: Medical Orders for Life Sustaining Treatment; **MOST**: Medical Orders for Scope of Treatment; **OkPOLST**: Oklahoma Physician Orders for Life-Sustaining Treatment; **POLST**: Physician Orders for Life-Sustaining Treatment; **POST**: Physician Orders for Scope of Treatment; **TOPP:** Transportable Orders for Patient Preferences; **TPOPP**: Transportable Physician Orders for Patient Preferences; **WyoPOLST**: Wyoming Providers Orders for Life Sustaining Treatment

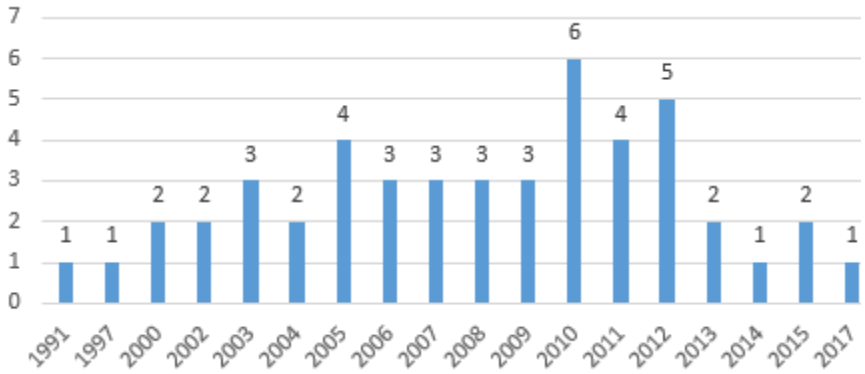

Figure 3. Year POLST program started (N=48)

Table 4. Variations in EoL Treatment Options presented on POLST Forms (n=45)

	Antibiotics	IV fluids	Transfer to Hospital	Medication by any route	Oxygen	BiPAP / CPAP	Intubation / Ventilation
POLST maturity status	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
POLST maturity status							
Mature	2 (66.67)	3 (100)	3 (100)	3 (100)	3 (100)	3 (100)	3 (100)
Endorsed	14 (73.68)	13 (68.42)	19 (100)	19 (100)	19 (100)	18 (94.74)	18 (94.74)
Developing	14 (70.00)	16 (80.00)	20 (100)	20 (100)	20 (100)	18 (90)	17 (85)
Non-Conforming	2 (66.67)	1 (33.33)	3 (100)	3 (100)	3 (100)	3 (100)	3 (100)
Frequency mentioned and locations							
Mentioned once							
Comfort Measures	13 (28.89)	0	0	45 (100)	45 (100)	0	0
Limited treatment	0	28 (62.22)	0	0	0	1 (2.22)	0
Full treatment	15 (33.33)	0	0	0	0	10 (22.22)	36 (80)
Separate Section	0	0	4 (8.89)	0	0	0	5 (11.11)
Mentioned Twice							
Comfort + Limited treatment	3 (6.67)	0	7 (15.56)	0	0	0	0
Limited + Full treatment	0	5 (11.11)	0	0	0	26 (57.78)	0
Limited + separate section	1 (2.22)	0	0	0	0	0	0
Full + separate section	0	0	0	0	0	0	0
Mentioned three time							
Comfort + Limited + Full treatment	0	0	34 (75.56)	0	0	0	0
Limited + Full + Separate section	0	0	0	0	0	0	0
Total mentioned	32 (71.11)	33 (73.33)	45 (100)	45 (100)	45 (100)	42 (93.33)	41 (91.11)
Not mentioned at all	13 (28.89)	12 (26.67)	0	0	0	3 (6.67)	4 (8.89)
Total	45 (100)	45 (100)	45 (100)	45(100)	45 (100)	45 (100)	45 (100)

Chapter 4: Impact of Physician Orders for Life-Sustaining Treatment (POLST) Program Maturity Status On The U.S. Nursing Home Resident's Place of Death

The following chapter is a multivariate logistic regression analysis we conducted to examine the impacts of POLST maturity status on U.S. NH resident outcome. Guided by previous HN research work as well as Behavioral Model, we conducted analysis using multiple large datasets and nationally representative sample of elderly individuals living with serious illnesses.

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Abstract

Background:
The Physician Orders for Life-Sustaining Treatments (POLST) program was developed to enhance quality of care delivered at end-of-life (EoL). Although positive impacts of POLST program use on dying individual's EoL care have been identified, the association between a state's POLST program maturity status and nursing home (NH) resident's place of death is unknown.

Aim:
Examine the impact of POLST program maturity status on elderly NH residents' place of death.

Design:
A national, retrospective, cross-sectional analysis was conducted.

Setting/ Participants:
Elderly NH residents not living in the Virgin Islands with Minimum Data Set (MDS) 3.0 assessment(s) documented between 2012 and 2013 and who died in 2013 either in the NH or within 90 days of last NH discharge. The final sample included 595,152 individuals.

Methods:
The POLST program data were linked with the following national-level datasets: MDS, Vital Statistics Data, Master Beneficiary Summary File, Certification and Survey Provider Enhanced Reports, and Area Health Resource File. Stratifying residents on long-stay and short-stay, we used descriptive statistics and multivariate logistic regression models to examine the impact of POLST maturity status on nursing home residents' place of death.

Results:
Controlling for individual and contextual variables, long-stay residents living in states where the POLST program was mature had 20% increased odds of dying in NHs (OR: 1.20; CI 1.02-1.43) compared to those who resided in states with non-conforming POLST program. Residents living in states endorsed or developing POLST status also had greater odds of dying in NHs (OR: 1.09; CI 0.98-1.21 endorsed status; OR: 1.12; CI 1.02-1.24 developing status) compared to the residents resided in states with non-conforming POLST status. No significant difference was noted for short-stay residents.

Conclusion:
Higher POLST maturity status was associated with greater likelihood of dying in NHs among long-stay nursing home residents. Our finding adds a new scientific evidence that a well-structured advance care planning program such as POLST enhances care outcomes among elderly patients living in NHs.

Introduction

There are over 16,000 U.S. nursing homes (NHs) serving nearly 1.5 million U.S. individuals at any time.[195] It is estimated 1 in 4 Americans will die in NHs,[196,197] and this number is projected to increase rapidly due to aging baby boomers, making end-of-life (EoL) care important in this setting.[196,198,199] NHs are a major healthcare settings for patients living with a wide array of medical needs, ranging from post-acute conditions needing rehabilitation care to seriously ill patients with continuous nursing needs until the time of death.[200,201] The vast majority of long-stay residents (i.e., those with a length of stay greater than 90 days) are the oldest of the old, individuals 85 years of age or older. These elderly residents suffer from complex health conditions and/or frailty,[195,197] which is defined as a clinical state where an individual is at increased vulnerability of experiencing adverse health outcomes.[202,203] For these vulnerable elderly residents, quality EoL care is a high priority.

Many experts have proposed domains of EoL care that can serve as quality indicators including: symptom management and care satisfaction,[204-206] advance care planning,[205-207] aggressiveness of care,[196,208] and place of death for long-stay residents.[206,209] Place of death for NH residents as an EoL quality care marker needs to be carefully considered because the care needs of long-stay NH residents are different than those of short-stay residents.[210,211] Contrary to the goals of care in short-stay residents, which focuses on complete recovery and return back to community, the goals of care for long-stay residents align towards optimizing the quality of life and relief of suffering due to irreversible cognitive impairments,[212-214] or progressively worsening physical impairments.[215,216] For these residents, death in acute care facilities (e.g., emergency rooms or hospitals) is often deemed inappropriate, as the evidence shows that hospital transfers and subsequent deaths are closely associated with increased physical and

financial burdens,[217] adverse health outcomes,[218] and receipt of aggressive or unwanted medical interventions.[209,219-222] For long-stay NH residents, hospital deaths have been identified as a marker for poor quality of EoL care.[198,211,223-225]

The Physician Orders for Life-Sustaining Treatment (POLST) paradigm is an advance care planning program that was developed by medical experts in Oregon.[19] POLST is a voluntary care planning tool, designed for individuals whose life expectancies are less than 12 months and are nearing the end of their lives.[67,226-229] It allows a dying patient or their family to document specific care preferences through EoL care discussions, and facilitate patient-centered care planning. In 2004, the POLST program was publicly acknowledged by the Institute of Medicine (now known as National Academy of Medicine) as a program that can help achieve high quality EoL care.[230]

To set the standards for the program recognition, the national POLST program task force established 4 levels of program maturity status: mature, endorsed, developing, and non-conforming.[19,66] *Mature* status indicates the highest endorsement level, where the POLST program (e.g., California's POLST) had become a part of the standard of care for individuals living with serious illnesses and limited life expectancies.[66] *Endorsed* status indicates that the state POLST program (e.g., New York's MOLST; M stands for medical) met key elements (e.g., having a single form for a state-wide usage), and have developed strategies for ongoing education and quality assurance.[19,66] *Developing* status indicate that the state POLST program (e.g., Ohio's MOLST) may be at an initial stage of development, and working towards statewide implementation. Lastly, *non-conforming* status (e.g., Nebraska's POLST) indicates the POLST program either does not exist, or the state program does not meet the national POLST program endorsement criteria (e.g., no agreement on single form use).

While the use of POLST program was positively associated with increased hospice referrals,[231,232] and EoL care discussions between care provider and terminally ill patients,[148],[28,233,234] an association between a state's POLST program maturity status and the potential impacts it has on NH residents outcomes remain unanswered.

Purpose

The purpose of this study is to examine the impact of POLST maturity status on the NH death among elderly residents. We hypothesized that the higher POLST maturity status was positively associated with a greater likelihood of dying in the NHs for long-stay residents.

Method

This national study is a retrospective, cross sectional analysis.

Data sources

We used data collected from a previous published POLST program environmental scan,[71] linked with national-level administrative datasets: 2014 Vital Statistics File, 2012-2013 Minimum Data Set 3.0 (MDS), 2014 Certification and Survey Provider Enhanced Reporting (CASPER), Area Health Resources File (AHRF) and the 2013 Master Beneficiary Summary File (MBSF).[71] All data were linked by facility identification or location.

The POLST environmental scan included data on: **a)** each state's POLST maturity status; **b)** time the state first adopted POLST program (measured in years); and when applicable, **c)** year the state underwent change(s) in its POLST program maturity status (i.e., obtained the next level of maturity status) as well as **d)** the total length of time in years it took to advance to the next maturity status (e.g., developed to endorsed, endorsed to mature). Using this comprehensive dataset, we used data on each U.S. state's POLST program maturity status, as of 2013.

The Vital Statistics File was used to identify U.S. NH residents who died in 2013. Resident-level data were extracted from the MDS, which is federally mandated clinical assessment

documentation of NH residents who are residing in Centers of Medicare and Medicaid Services (CMS) certified nursing facilities.[235] Detailed health assessments are recorded on MDS upon admission, quarterly thereafter, and when any significant changes (i.e., transfer or death) occur. An assessment contains individual's demographic information, as well as health information (i.e., functional status).[236] To obtain the most comprehensive resident-level data, we used the last available annual or the quarterly Omnibus Budget Reconciliation Act /Prospective Payment System (OBRA/PPS) assessment type prior to death for our long-stay group. For short-stay group, we utilized the PPS assessment type (i.e., 5-day, 14 day or 30 day scheduled assessment; whichever was the most recent). Resident characteristics extracted were: age at death, sex, race/ethnicity, and date of NH admission and discharge (when applicable); assessments on bed mobility, transfer, toilet use were extracted to compute the total activities of daily living (ADL) score for study sample.[237]

The CASPER dataset contains facility level information collected during the state annual inspection surveys of NHs. Submission of such data is required by CMS, as a part of quality assurance system.[238] Facility-level characteristics extracted included ownership, membership affiliation/ chain, bed size, occupancy rate, staffing and the presence of special units (i.e., Alzheimer's and/or hospice unit). The decision to include the presence of special units in NHs was guided by recent publications,[239,240] which noted that the presence of the special units were related to residents' health outcomes.

The AHRF is a county level dataset, which contains in-depth information on health resources, environmental, and sociodemographic characteristics of each county in the US.[241] The following information were extracted from the dataset: proportion of elderly (>65 years) population in county, and median household income.

The MBSF contains data on all Medicare beneficiaries who are enrolled in, or entitled to receive Medicare benefit within a given calendar year.[242] There are total 4 segments to the MBSF dataset: 1) beneficiary enrollment information summary; 2) chronic conditions; 3) cost and utilization; 4) national death index. We utilized chronic conditions segment, which informs whether an individual had select chronic health conditions in their last year of life. Chronic conditions identified through this segment were Alzheimer's disease, dementia, chronic kidney disease (CKD), diabetes, cancer, and chronic obstructive pulmonary disease (COPD).

Study Sample

Using the 2014 Vital Statistics File, we identified 1,009,372 unique individuals who died in 2013. The sample process is depicted in **Figure 5.** Exclusions applied to our study sample were: individuals with no MDS assessment documented in 2012 or 2013 (n = 142,873), unable to merge with CASPER or AHRF data due to issues including inaccurate facility identifier or county code (n = 67,841), did not have MBSF information (n = 320), younger than 65 years of age, and living in the Virgin Islands (n = 33,947). Our final study sample included total of 595,152 unique individuals. Guided by previous NH studies and based on our hypothesis,[243-245] we further classified our sample into long-stay (with consecutive length of stay equal or longer than 90 days, n = 285,888) or short-stay (length of NH stay less than 90 days, n = 309,264) residents.

Outcome variables

The outcome of interest was place of death, dichotomized as NH death = 1, non-NH death = 0. Using the resident's last MDS assessment, NH death was *yes* if **a**) resident's discharge placement indicated *deceased*, or **b**) MDS assessment type indicated *death in facility*. NH death was marked as *no* if **a**) MDS assessment type indicated *discharge reporting* and **b**) resident's

discharge placement indicated that the resident was discharged to one of following settings: community; another NH facility; acute hospital; psychiatric hospital; inpatient rehab; Intellectual/ Development Disability (ID/DD) facility; hospice; long-term care hospital; or other.

Predictor variables

The main predictor of interest was the POLST program maturity status: mature, endorsed, developing and non-conforming.[71] Guided by previous NH studies, individual and contextual characteristics associated with place of death in NHs were also examined. These characteristics were classified according to the Gelberg-Andersen's Behavioral Model (shown in **Figure 4**). This model identifies an individual's access to healthcare services and/or pattern of healthcare as a function of three main domains: predisposing, enabling and need factors.[125,246] Individual characteristics included as the predictors of NH death were: resident's age (65-70 years, 71-75 years, 76-80 years, 81-85 years, 86-90 years, 91-95 years, 96-100 years, 101-110 years), sex (male vs. female), race/ ethnicity (Non-Hispanic White, African American, American Indian, Asian, Hispanic, Native Hawaiian/Pacific Islander, or 2 or more race), marital status (married, never married, separated, widowed, or divorced), chronic conditions (present or absent of; cancer, COPD, CHF, diabetes, CKD, Alzheimer's, dementia), and the total ADL score (range 4-18).[225,243,247-249] Facility level predictors were: presence of special unit (yes vs. no for; Alzheimer's unit, hospice unit) and bed size (<50, 50-99, 100-199, >200).

Other contextual variables that were controlled for included facility-related and county-related characteristics. Facility-related characteristics were: NH type (for-profit, non-profit, government), affiliation or chain status (yes vs. no), occupancy rate (range 0-100 percent), staffing (measured in number of hours per resident day for: registered nurse, license practical nurse, and certified nurse assistant), profit status (non-profit, non-profit or government owned),

proportion of elderly population ≥65 years (range: 1-40 percent), and median household income (low, middle, high),[241,250] setting (metropolitan, urban, rural), and geographic regions (West, Midwest, Northeast or South).[209,223,241,247]

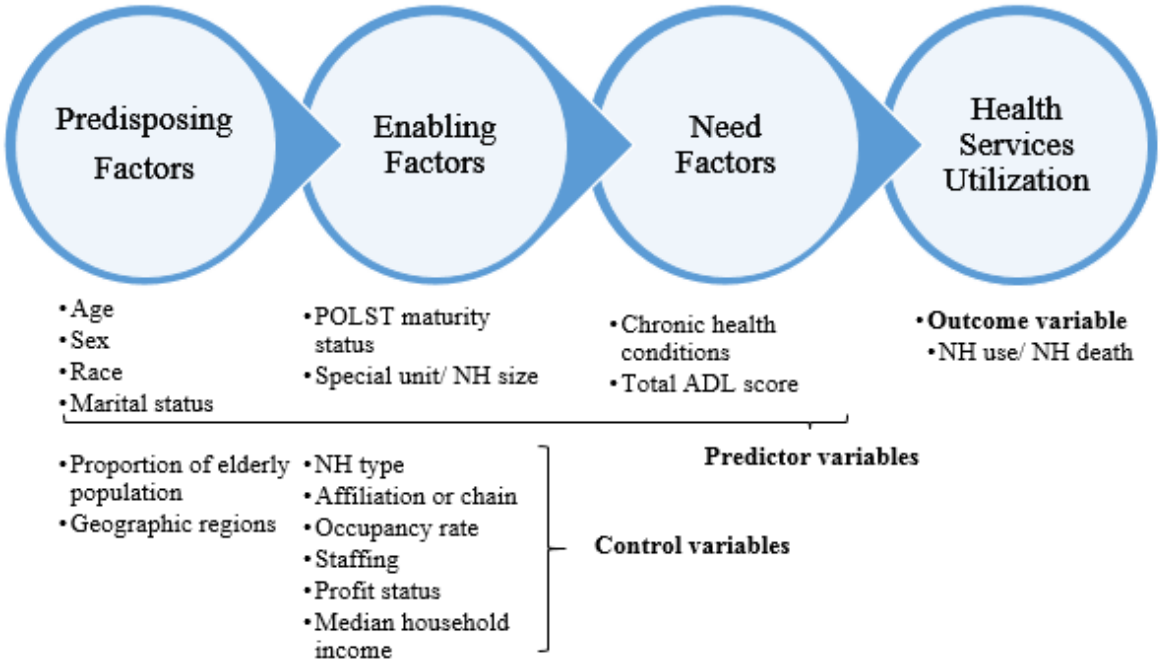


Figure 4. Theoretical Framework and Variables Included

note: ADL: activities of daily living; NH: nursing home; POLST: physician orders for life-sustaining treatment.

Analysis

Descriptive statistics (i.e., frequencies, means, standard deviations, and percentages) were used to summarize characteristics of study sample and NH facilities, stratified by stay types (i.e., long-stay, short-stay) and then the total sample combined. Bivariate analyses were conducted to investigate associations between baseline characteristics and NH death. Chi-square and t-test statistics were used to examine if there were significant differences between each variable in the model and NH death, across long and short-stay types.

Using multivariate logistic regression, we calculated associations between POLST maturity status and place of death, stratified by long and short-stay. To account for the non-

independence of observations derived from repeated measures of NH facilities within the same county, we estimated county-clustered robust standard errors. Odds ratio (OR) and 95% confidence intervals (CI) were calculated. All analyses were conducted using SAS 9.4.

Results

Resident level characteristics

Baseline characteristics of study sample are presented in **Table 5**. The total study sample included 595,152 unique elderly individuals who died in 2013. Forty eight percent of sample population were long-stay (n = 285,888) and 52% were short-stay residents (n = 309,264). Together, they represent a total of 6,241 NHs across the nation. Except for the presence of hospice unit (p = 0.09) within NH facilities, all other variables included in our study were significantly different across the long and short-stay group (p<.0001).

The sample residents were predominantly female (61%), non-Hispanic White (85%), and died between the ages of 86-90 (24%). The average age at death for the total sample was 84 years (SD ± 8.35). Nearly half (49%) of our sample were in oldest old age group, age 86 and older. Little over half of total sample (52%) reported their marital status as widowed. The proportion of those with widowed marital status were higher among long-stay residents (58%) than in short-stay (46%) residents (p<.0001). The most common chronic conditions seen across the stay types were CHF (50%) and CKD (48%). Although the total proportion of sample residents who suffered from Alzheimer's disease were 29%, the proportion was much higher among long-stay residents than short-stay residents (41% vs. 17%, respectively, p<0.001). Similarly, the total proportion of cancer patients in our sample residents were 14%. However, the proportion of cancer patients were much higher among short-stay residents than long-stay residents (19% vs. 8%, respectively, p<.0001).

Little over half (57%) of total sample residents died in NHs. NH deaths were more common among long-stay residents than short-stay residents (76% vs 41% respectively, $p<.0001$).

State POLST program characteristics

The majority of states (59%) had a POLST program with *developing* maturity status, followed by *endorsed* (35%), *non-conforming* (5%) and *mature* (1%). Nearly all (95%) of sample residents (i.e., 95% of all long-stay and 96% of all short-stay residents) were from the states where the POLST program had developing or higher maturity status.

Contextual characteristics

The contextual variables included in our study are presented in **Table 6.** Most of sample facilities had for-profit status (72%), and were chain affiliated (57%). More than half (59%) of sample NHs were equipped with 100 to 199 beds, with an average occupancy rate of 84% (± 13.60). The average nursing staff (measured in number of hours per resident day) varied; 0.74 hour per resident day for registered nurses (SD ± 0.43), 0.84 hour per resident day for licensed practical nurses (SD ± 0.35), and 2.16 hour per resident day for certified nursing assistant (SD ± 0.65). Twenty two percent of all NHs were equipped with Alzheimer's unit, whereas only a small fraction had hospice unit (1%).

Sample NHs were mainly located in the South (36%), and in metropolitan areas (81%). An average proportion of elderly population per county was 10% (SD ± 3.27), and the median household income per county was $53,334.54 (SD ± 13,957.46)

Impact of POLST maturity status on NH death

Table 7 shows the result of multivariate logistic regression analysis stratified by stay type. In the long-stay residents, the odds of dying in NHs were 20% higher in states that had

mature POLST programs compared to states where the POLST program was *non-conforming* (OR: 1.20, 95% CI 1.02-1.43). Similarly, residents in a state where the POLST program had *endorsed* or *developing* status had 9% (OR: 1.09, 95% CI 98-1.21) and 12% (OR: 1.12, 95% CI 1.02-1.24) increased odds of dying in NHs compared to residents in states where the POLST program was *non-conforming*. There was no significant difference for short-stay residents.

Predictors of NH death by Stay Type

In long-stay residents, older age groups had progressively higher likelihood of dying in NHs (ORs: 1.07-4.44). Older age and the higher likelihood of NH deaths remained constant in the short-stay group (ORs 1.04-2.88). Although odds of dying in NHs were not statistically different between the reference group (65-70 years) and the second youngest age group (71-75 years); all other age groups had progressively higher odds of dying in NHs (OR: 1.04, 1.19, 1.35, 1.63, 1.91, 2.23 for age group 76-80, 81-85, 86-90, 91-95, 96-100, 101-110, respectively)

In both long and short-stay residents, individuals who were never married, divorced, separated, or widowed had higher likelihood of dying in NHs (ORs: 1.10-1.57). In a long-stay group, separated marital status was the strongest predictor of NH deaths (OR: 1.27, 95% CI 1.14-1.40) compared to the married status. On the other hand, never been married was the strongest predictor of NH deaths for the short-stay residents (OR: 1.52, 95% CI 1.47-1.57).

In the long-stay residents, compared to White race, all other race groups (i.e., African American, American Indian, Asian, Hispanic, Native Hawaiian/ Pacific Islander, 2 or more race) had lower odds of dying in NHs (ORs: 0.66-0.71). In the short-stay residents, those who were Asian or multiple race (e.g., 2 or more races) had higher odds of dying in NHs (OR 1.22, 1.35, 95% CI 1.07-1.38, 1.15-1.58, respectively).

Having COPD increased likelihood of death in NHs compared to those who did not have COPD (OR: 1.49, 95% CI 1.45-1.53 long-stay; OR: 1.20, 95% CI 1.18-1.23 short-stay). Alzheimer's disease also increased likelihood of dying in NHs, compared to those who did not have Alzheimer's diagnosis (OR: 1.49, 95% CI 1.44-1.54; OR: 1.45, 95% CI 1.42-1.48, respectively). An inverse relationship was noted in likelihood of dying in NHs for the NH residents suffering from cancer (OR 0.83, 95% CI: 0.81-0.86 for long stay; OR: 1.18, 95% CI 1.15-1.20 for short stay).

Facility characteristics associated with greater odds of dying in NHs were the presence of Alzheimer's unit (OR: 1.15, 95% CI 1.11-1.20 for long-stay; OR 1.16, 95% 95% CI 1.08-1.21 for short-stay), and the smaller NH facilities with less than 50 beds (OR: 1.16, 95% CI: 1.09, 1.24 for long-stay; OR1.12, 95% CI: 1.10-1.28 for short-stay), compared to a the reference group (NHs with bed size 50-99). NHs equipped with hospice unit was a significant predictor of NH death in both long-stay (OR: 1.05, 95% CI: 0.88-1.24) and short-stay group (OR: 1.15, 95% CI: 0.83-1.59).

Discussion

This is the first study to examine the association between the POLST program maturity status and NH deaths. Use of multiple large datasets, combined with a primary data collected through previous POLST study provide a new insight to better understand the impact of the POLST program maturity status and an associated patient outcome. Controlling for individual and contextual characteristics, we found that the higher POLST maturity status was positively associated with greater odds of dying in NHs, among long-stay residents.

While the data used in this study do not allow for assessing individual preferences and completion of POLST forms, the notable finding of a significant relationship between the state's POLST maturity status and increased NH death in long-stay residents, implies that the state-wide

adoption of POLST can promote positive care outcomes, beyond the individual resident's POLST form completion status. *Spill-over* is a term that explains the effects of an intervention on individuals who did not directly receive intervention, but who were connected to intervention recipients through social proximity.[251] It is often mentioned in NH studies where researchers witness an overall improvement of care outcome after initiating a new program that is designed for a target population (e.g., hospice program for dying patients).[113,114,243,251-254] Miller and colleagues reported that when the NH facility had higher number of hospice program enrollees, indicating higher exposure to a specialized EoL care program for all residents, care outcomes such as better management of pain,[81] more frequent pain assessment,[79,81] and reduced number of burdensome transfers to hospitals were seen throughout all residents, regardless of their hospice enrollment status.[114,115,124] This *spillover* phenomenon is thought to be caused by diffusion of knowledge.[255] That is, a newly implemented program or protocol generates new knowledge, which then fuels changes in the practice pattern or culture of institution, influencing care outcomes in general population. The pattern we observed, higher POLST maturity status and greater odds of dying in NHs among long-stay residents, may be in part due to increased knowledge generated with the initiation of state-wide adaptation of the POLST program that aims to emphasize importance of delivering patient-centered care for those who are nearing EoL.

While we observed significant associations between NH deaths and the state's POLST status (*developing* and *mature*), the positive association between *endorsed* status and NH deaths lacked significance. The previous research on POLST has only looked at care outcomes measured from those who completed the POLST forms,[73,232,233,256-260] making it difficult to draw a comparison with our results. It is possible that there could be a plateau period, where relatively small efforts are being made to change the practice pattern once the state's POLST program

obtains *endorsed* status, until they achieve the next, and the highest status, *mature*. It is also probable that NHs located in states with *endorsed* POLST status have an improved awareness on the importance of delivering specialized EoL care for dying patients, resulting in increased number of timely referrals to specialized EoL care facilities such as hospices or palliative care centers. Or, it could also be that those NHs put more efforts to identify dying patients' preferred place of death and allow them to be discharged from NHs near the time of death to honor patient wishes. Reasons behind the lack of significant association between the *endorsed* POLST status and NH deaths is an important question left to be answered through future studies.

Predictors of NH deaths

We found several resident-level factors that were significantly associated with NH death. Specifically, older age, White race, and living with chronic conditions (e.g., COPD, Alzheimer's disease, and/ or Dementia) were shown to increase the residents' odds of dying in NHs in both short and long-stay groups. Previous NH studies, which explored predictors of NH death in elderly residents, also reported similar findings; advanced age,[119,261-264] and chronic conditions were the most commonly found predictors of NH death for elderly residents living with serious illnesses.[261,262,264-266]

Although we noted a significant association between the race/ ethnicity and odds of dying in NHs in both stay groups, previous studies mixed results. For example, in a recent study of elderly individuals living with serious illnesses, authors did not find significant associations between individual's race/ ethnicity and the final place of death (e.g., hospital vs. non-hospital setting).[267] In another study, where authors examined the factors associated with in-hospital deaths among NH residents in two groups; non-Hispanic Black and non-Hispanic White

residents. It was noted that Black race was associated with a significantly higher odds of dying in hospitals, as opposed to NHs, when compared to their White counterparts.[268]

Male sex was noted to be significantly associated with the increased risk of NH death, in our short-stay group. While many studies have explored sex differences and the associated risk of mortality among NH residents,[262,269-273] none of identified studies reported specific location of death (e.g., NH vs. hospital). Moreover, the majority of available studies limited their study sample to disease-specific groups (e.g., Alzheimer's disease),[270,271,273] or by their cognitive fuction.[262,269] For instance, Lupane and colleagues found that male sex was a significant predictor of mortality among elderly NH residents living with Alzheimer's disease.[270] Another study also showed that male sex was significantly associated with increased mortality, among elderly residents living with Parkinson's Disease.[271]

There are few recommendations for future studies. First, future studies should conduct similar analysis using different measures that can be a surrogate measure for the level of POLST development, other than the maturity status. It can be a measure of total length of time since the POLST program was first initiated, or a composite score generated with different elements that are deemed important and relevant to the POLST program (e.g., research efforts, staff awareness, actual number of POLST form completed). By doing so, it can help determine if findings are consistent throughout studies and identify areas that needs further improvements.

Second, although we specifically focused NH death as our outcome of interest, future studies should examine the impact of POLST program/ maturity status on different outcomes (e.g., receipt of concordant interventions, number of hospice enrollments). Lastly, future research should also explore if different level of maturity status is associated with best practices in EoL care, such as timely EoL discussions, family meetings and/or bereavement supports.

Implications

In last few years, a significant research effort has been made to provide scientific evidence on benefits of high quality EoL care provided to vulnerable population. And previous studies unanimously support that best practices in EoL are those that maximize quality of remaining life, while minimizing avoidable care transfers. Results of this study call for the continued effort to adopt nationwide implementation of the POLST program that aims to deliver goal-concordant EoL care to elderly living with serious illnesses. It also calls for continued research efforts to identify best practices in EoL, and how best to deliver a type of care that aligns with dying patient's wishes, goals and values.

Limitations

There are several limitations to this study. Rather than dichotomizing our outcome of interest as NH vs. non-NH death, examining other outcomes (i.e., death occurring in community) could have offered findings that were not discussed in our study. Plus, specifying place of death, beyond NH settings, could have potentially shed light to the possible associations between the POLST maturity status and one's likelihood of dying at specific setting (e.g., home, NH, hospital). However, this was not feasible with the datasets we used. For instance, the current MDS 3.0 assessment includes an item that can help identify if the resident's last discharge (before the date of death) was to the *community*, or other facilities such as *acute care hospital*. The challenge that exists in using *community* as a measure of deaths that occurred at home is that the term *community* in MDS 3.0 includes other settings (i.e., assisted living care settings, or group homes). Needless to say, those settings are not the same as one's residence.

A similar problem arose when the patient's discharge placement indicated a discharge to a *hospice* setting. Although it may seem more appropriate that dying patient should receive

specialized care at hospice settings, it was unclear whether it captures discharges to a separate hospice care center, or a hospice unit within the same facility.

Another limitation of our study is related to the study design. Due to the nature of cross-sectional analysis, the relationship we examined between the POLST maturity status and NH death can only be interpreted as an association, and not causation. Statistical methods such as fixed effect model allows an analysis of the impact that variables carry over time. While it is useful to apply, we unable to apply state fixed effect as there was no variation in state POLST program maturity status.

Future study that addresses similar research question should be conducted to better understand the impact of the POLST program on individual level outcomes as well as the differences in maturity status and associated outcomes. While randomized control trials may not be feasible, a well-designed prospective studies and longitudinal studies can certainly add body of knowledge on this important topic.

Conclusion

Controlling for individual and contextual variables, higher POLST maturity status is positively associated with greater likelihood of dying in NHs, among long-stay residents. Findings from our study adds to the body of science that well-structured advance care planning programs, such as POLST, can promote best practices in EoL.

State-wide implementation of the POLST program, and continued efforts to meet high standards of quality EoL care (evidenced by higher maturity status) can result in positive health outcomes for elderly patients suffering from serious illnesses. State, or national-wide initiatives focusing on quality improvement at EoL should therefore be widely disseminated and adopted to provide best care possible for the most vulnerable populations.

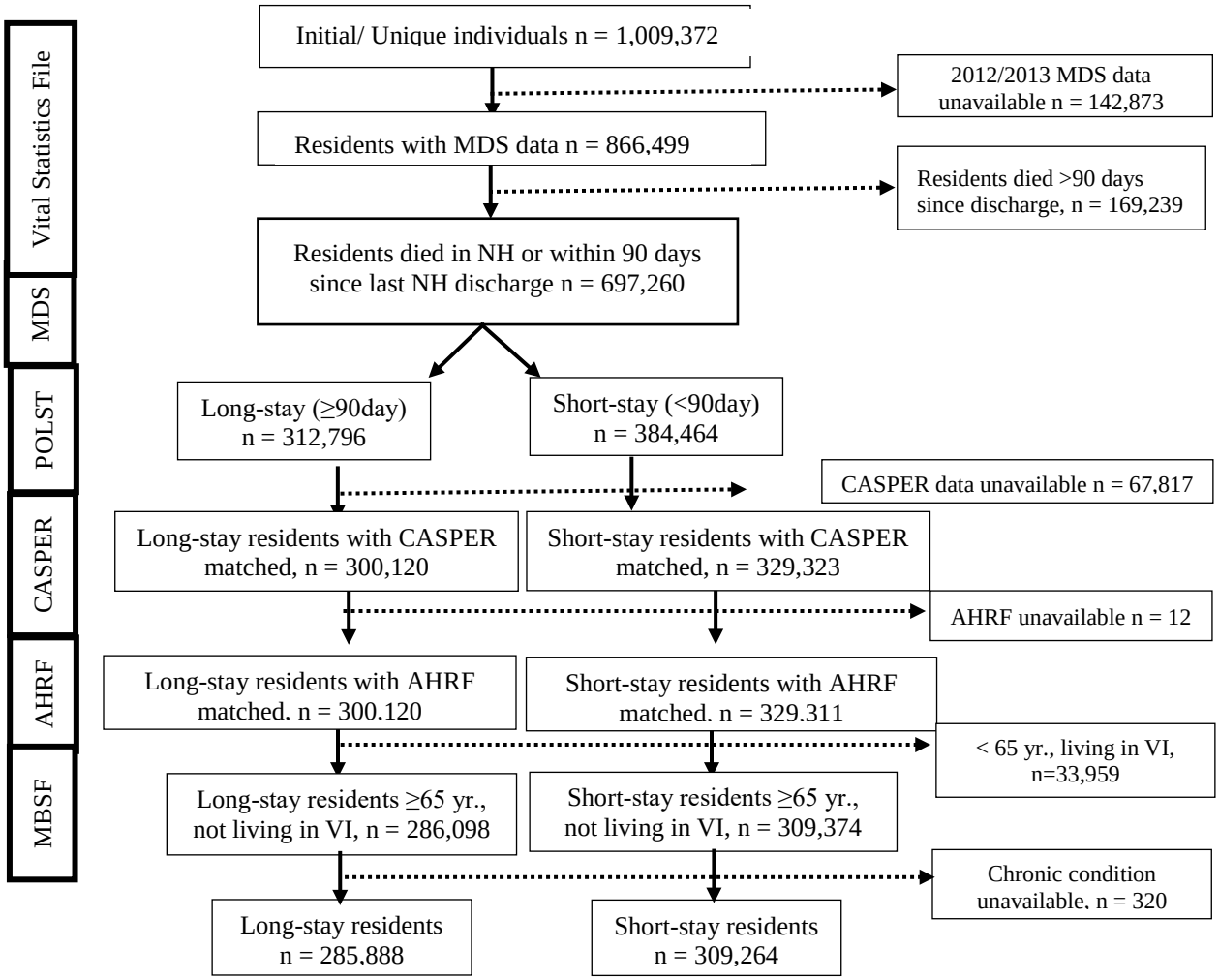


Figure 5. Sampling Process

Note: AHRF: area health resource file; CASPER: certification and survey provider enhanced reports; MBSF: master beneficiary summary file; NH; nursing home; POLST: physician orders for life-sustaining treatment; VI: virgin island

Table 5. Description of Resident Level Characteristics and Bivariate Associations by Stay Type.

Characteristic	Long-stay residents (n = 285,888)	Short-stay residents (n = 309,264)	Total sample (n = 595,152)	P value[1]
Individual characteristics, n (%)				
Sex				<.0001
Female	194,161 (67.92)	167,473 (54.15)	361,634 (60.77)	
Race/ Ethnicity				<.0001
African American	28,775 (10.24)	25,838 (8.61)	54,613 (9.39)	
American Indian	659 (0.23)	653 (0.22)	1312 (0.23)	
Asian	3,891 (1.38)	4,204 (1.40)	8,095 (1.39)	
Hispanic	9,769 (3.47)	9,282 (3.09)	19,051 (3.28)	
Two or more race	577 (0.21)	598 (0.20)	1,175 (0.20)	
Native Hawaiian	272 (0.1)	344 (0.11)	616 (0.11)	
Non-Hispanic White	237,193 (84.37)	259,270 (86.37)	496,463 (85.40)	
Age at death				
65-70	17,237 (6.03)	31,332 (10.13)	48,569 (8.08)	<.0001
71-75	21,330 (7.46)	34,395 (11.12)	55,725 (9.29)	
76-80	33,574 (11.74)	46,933 (15.18)	80,507 (13.46)	
81-85	55,148 (19.29)	65,855 (21.29)	121,003 (20.29)	
86-90	71,612 (25.05)	71,140 (23.00)	142,752 (24.03)	
91-95	58,318 (20.40)	42,569 (14.64)	100,887 (17.52)	
96-100	23,824 (8.33)	12,765 (4.13)	36,589 (6.23)	
101-110	4,845 (1.69)	1,575 (0.51)	6,120 (1.10)	
Marital Status				
Divorced	25,933 (9.18)	24,509 (8.12)	50,442 (8.64)	<.0001
Married	62,637 (22.18)	111,973 (37.12)	174,610 (29.89)	
Never Married	27,671 (9.80)	22,751 (7.54)	50,422 (8.63)	
Separated	2,579 (0.91)	2,418 (0.80)	4,997 (0.86)	
Widowed	163,596 (57.93)	140,027 (46.42)	303,623 (51.98)	
Chronic Conditions				
Alzheimer	116,110 (40.61)	53,939 (17.44)	170,049 (28.57)	<.0001
Dementia	103,570 (36.23)	81,750 (26.43)	185,320 (31.14)	<.0001
CKD	122,948 (43.01)	162,208 (52.45)	285,156 (47.91)	<.0001
CHF	140,126 (49.01)	159,924 (51.71)	300,050 (50.42)	<.0001
Diabetes	109,363 (38.25)	109,918 (35.54)	219,281 (36.84)	<.0001
Cancer	23,294 (8.15)	58,484 (18.81)	81,478 (13.69)	<.0001
COPD	66,051 (23.10)	99,614 (32.21)	165,665 (27.84)	<.0001
Death in NH	216,182 (75.62)	125542 (40.59)	341724 (57.42)	<.0001

Note: ADL: activities of daily living; CKD: chronic kidney disease; COPD: chronic obstructive pulmonary disease; LPN: licensed practical nurse; NH: nursing home; SD: standard deviation;
[1]: P value from chi-square tests for categorical variables, and t test for continuous variables
[2]ADL score range 4 to 18 (4 = independent, 18 = total dependency)

Table 6. Description of NH Sample and Bivariate Associations, by Stay Type.

Characteristic	Long-stay residents (n = 285,888)	Short-stay residents (n = 309,264)	Total sample (n = 595,152)	P value[1]
	Independent variable, n (%)			
POLST maturity status				<.0001
Mature	3,377 (1.18)	4,829 (1.56)	8,206 (1.38)	
Endorsed	101,632 (35.55)	108,566 (35.10)	210,198 (35.32)	
Developing	167,370 (58.54)	182,356 (58.96)	349,726 (58.76)	
Non-conforming	13,509 (4.73)	13,513 (4.37)	27,022 (4.54)	
	Facility characteristics, n (%)			
Facility type				<.0001
For-profit	198,680 (69.50)	230,622 (74.57)	429,302 (72.13)	
Non-profit	70,245 (24.57)	69,320 (22.41)	139,565 (23.45)	
Government	16,963 (5.93)	9,322 (3.01)	26,285 (4.42)	
Affiliation/ Chain	154,981 (54.21)	184,326 (59.60)	339,307 (57.01)	<.0001
Bed size				<.0001
< 50	8,779 (3.11)	10,844 (3.55)	19,623 (3.34)	
50-99	71,803 (25.44)	75,284 (24.63)	147,087 (25.02)	
100-199	161,173 (57.11)	184,343 (60.32)	345,516 (58.78)	
>200	40,462 (14.34)	35,135 (11.50)	35,135 (11.50)	
Occupancy rate	85.06 (12.89)	83.82 (14.19)	84.41 (13.60)	<.0001
Staffing				
RN	0.69 (0.34)	0.81 (0.49)	0.75 (0.43)	<.0001
LPN	0.82 (0.33)	0.86 (0.37)	0.84 (0.35)	<.0001
CNA	2.44 (0.60)	2.48 (0.69)	2.16 (0.65)	<.0001
Occupancy rate	85.06 (12.89)	83.82 (14.19)	84.41 (13.60)	<.0001
Special unit				
Alzheimer's unit	62,853 (21.99)	54,355 (17.58)	117,208 (19.69)	<.0001
Hospice unit	2,904 (1.02)	3,279 (1.06)	6,183 (1.04)	0.09
	County level characteristics mean (SD)			
Elderly proportion	10.11 (3.86)	9.95 (3.59)	10.03 (3.72)	<.0001
Median household income	52484.29 (13670.26)	54120.59 (14172.54)	53334.54 (13957.46)	<.0001
	County level characteristics, n (%)			
Setting				<.0001
Metropolitan	221548 (77.50)	261631 (84.60)	483,179 (81.19)	
Urban	57740 (20.20)	43867 (14.19)	101,607 (17.07)	
Rural	6569 (2.30)	3750 (1.21)	10,319 (1.73)	
Geographic region				<.0001
Midwest	82,204 (28.75)	79,062 (25.57)	161,266 (27.10)	
Northeast	72,731 (25.44)	71,675 (23.18)	144,406 (24.27)	
South	102,059 (35.70)	110,709 (35.80)	212,768 (35.75)	
West	28,891 (10.11)	47,767 (15.45)	76,658 (12.88)	

Note: CNA: certified nursing assistance; LPN: licensed practical nurse; NH: nursing home; POLST: physician orders for life-sustaining treatment; SD: standard deviation;
*: measured in full-time equivalent hours per resident per day
[1]: P value from chi-square tests for categorical variables, and t test for continuous variables

Table 7. Multivariate logistic regression model by NH stay type

Predictors	Long-Stay Residents		Short-Stay Residents	
	OR	**(95% CI)**	**OR**	**(95% CI)**
POLST maturity status				
Mature	1.20	(1.02-1.43)	0.90	(0.75-1.09)
Endorsed	1.09	(0.98-1.21)	1.12	(0.99-1.26)
Developing	1.12	(1.02-1.24)	0.97	(0.86-1.10)
Non-Conforming	Reference		Reference	
Age (in years)				
65-70	Reference		Reference	
71-75	1.14	(1.07-1.20)	1.008	(0.98-1.04)
76-80	1.27	(1.22-1.33)	1.09	(1.04-1.13)
81-85	1.46	(1.41-1.52)	1.23	(1.19-1.27)
86-90	1.71	(1.65-1.78)	1.41	(1.35-1.47)
91-95	2.12	(2.03-2.21)	1.70	(1.63-1.78)
96-10	2.74	(2.60-2.88)	2.02	(1.91-2.14)
101-110	4.02	(3.63-4.44)	2.54	(2.23-2.88)
Sex				
Female	Reference		Reference	
Male	0.995	(0.97-1.01)	1.07	(1.05-1.09)
Marital Status				
Married	Reference		Reference	
Never Married	1.14	(1.10-1.19)	1.52	(1.47-1.57)
Divorce	1.17	(1.13-1.22)	1.38	(1.33-1.43)
Separated	1.27	(1.14-1.40)	1.31	(1.18-1.45)
Widowed	1.12	(1.09-1.15)	1.21	(1.18-1.23)
Race/ Ethnicity				
Non-Hispanic White	Reference		Reference	
African American	0.69	(0.66-0.73)	0.85	(0.81-0.89)
American Indian	0.68	(0.55-0.82)	0.87	(0.72-1.05)
Asian	0.66	(0.62-0.71)	1.22	(1.07-1.38)
Hispanic	0.68	(0.64-0.73)	0.90	(0.84-0.95)
Native Hawaiian/ Pacific Islander	0.66	(0.50-0.87)	0.80	(0.64-0.99)
2 or more race	0.71	(0.59-0.86)	1.35	(1.15-1.58)
Chronic Conditions				
Cancer	0.83	(0.81-0.86)	1.18	(1.15-1.20)
COPD	1.49	(1.45-1.53)	1.20	(1.18-1.23)
CHF	0.72	(0.70-0.73)	0.80	(0.78-0.81)
Diabetes	0.92	(0.90-0.94)	0.97	(0.95-0.99)
CKD	0.49	(0.47-0.49)	0.75	(0.73-0.76)
Alzheimer's	1.49	(1.44-1.54)	1.45	(1.42-1.48)
Dementia	1.33	(1.30-1.37)	1.24	(1.21-1.26)
Alzheimer's Unit	1.15	(1.11-1.20)	1.14	(1.08-1.21)
Hospice Unit	1.05	(0.88-1.24)	1.15	(0.83-1.59)
Bed Size				
50-99	Reference		Reference	
<50	1.16	(1.09-1.24)	1.18	(1.10-1.28)
100-199	0.92	(0.90-0.95)	0.82	(0.79-0.86)
>200	0.81	(0.76-0.89)	0.72	(0.67-0.77)

Note: CI: confidence interval. CHF: congestive heart failure; CKD: chronic kidney disease; COPD: chronic obstructive pulmonary disease; NH: nursing home; OR: odds ratio

All models controlled for state-level clustering effects, state-level fixed effects, sociodemographic characteristics (i.e., total ADL score), and facility level characteristics (i.e., staffing, occupancy rate, facility type, affiliation/chain status, setting, geographic region), county level characteristics (i.e., proportion of elderly, median household income)

Chapter 5: Synthesis

This closing chapter first synthesizes findings of research studies included in this dissertation. It then presents discussion of research findings in the context of existing evidence and implications for policy, clinical practice and future research. Finally, strengths and limitations of studies included in this dissertation are described.

Summary of Study Findings

Our systematic review, described in chapter 2, aimed to synthesize scientific evidence on the rate of congruence between the care wishes documented on the Physician Orders for Life Sustaining Treatments (POLST) form and the actual care delivered during end-of-life (EoL) care journey. High rate of congruence was noted on the level of medical care requested (e.g., comfort -focused, limited or full interventions); preferred care settings (e.g., hospital or nursing home; NH); and the delivery of cardiopulmonary resuscitation (CPR). Mixed concordance rates were found in the use of antibiotics and feeding tubes at EoL. It was noteworthy that none of patients who opted not to receive CPR had unwanted CPR performed at the time of death.

Our study results were in line with the findings that were reported from the previous review. Hickman and colleagues authored a 2015 study,[21] which found high congruence in CPR and hospital transfer interventions, with low to mixed rates for feeding tube and antibiotics usage. Although the Hickman study had a similar research question our systematic review offered broader and generalizable findings by expanding study inclusion criteria. That is, while the a previously review only examined the sample population who were residing in clinical settings (e.g., hospital or hospice), we included study sample to that of community indwellers, and home-based care recipients.

The environmental scan study we conducted in chapter 3 was to examine the current status of the POLST program implementation across the nation. Using a national and state-specific POLST program websites, we were able examine: whether each state implemented the POLST program; maturity status of state POLST programs; year it established/ endorsed/ matured (when applicable); and specific care options captured on the state POLST forms. In addition, we extracted care options that were related to infection and symptom management, to

investigate whether presence of such EoL care options were significantly associated with the POLST maturity status.

This study revealed that the majority states (n = 48, 98%) were actively participating in the POLST program. There were 19 states (39%) with endorsed status, 3 states (6%) with mature status. While care options for the CPR delivery, oxygen use, hospital transfer and medication administration were present in nearly all available POLST forms (n = 45, 100%), antibiotics use was the least frequently mentioned option of all (n = 32, 71%). We also found that there no association between the maturity status and the presence of infection/symptom management options. Being the first study to ever examine current status of the POLST program across the nation, this study significant contributed to the knowledge of where we stand, in terms of effort to enhance EoL care processes and deliveries.

Lastly, we conducted quantitative analysis to examine the impact of POLST maturity status on NH death, using a multivariate logistic regression model. Our sample constituted of a nationally representative sample of elderly individuals, who died in 2013 and resided in NHs between 2012-2013. Variables used in the model were guided by Andersen's Behavioral Model, as well as previous research studies that explored risk factors related to place of death among elderly individuals.

Controlling for all other factors (i.e., individual and contextual characteristics), increased odds of dying in NHs were noted among long-stay residents residing in higher POLST maturity status (non-conforming status serving as reference). There was no significant association noted in short-stay residents. This was the first study that used a novel approach to examine the impact of the POLST status and associated outcomes within NH settings. In addition, we were able to

identify several important factors, that were shown to significantly associated with NH deaths in vulnerable population. Summary of findings from each study is depicted in **Table 8.**

Table 8. Summary of Each Study and Its Findings

Study 1

Aim: Synthesize the evidence on the congruency between Physician Orders for Life-Sustaining treatment (POLST) documentation and subsequent care delivered to End-of-Life (EoL) for U.S. residents

- **Title**: *Congruence between End-of-Life Care Preferences using Physician Orders for Life-Sustaining Treatment (POLST) documentation and subsequent care delivered: Systematic Review*

- **Findings**
  - Eight research studies included, examined the rate of congruence between care wish documented and delivered, from carious care settings (e.g., Nursing Home, Hospital, Community, and Hospice care settings)
  - The range of congruence was: 84-100% for Cardio-pulmonary Resuscitation; 85-87% for hospital transfers; 64-86% for antibiotics use; and 50-94% for feeding or IV fluid use

Study 2

Aim: Examine current status of POLST program implementation across U.S., and identify state variations in how infection and physical symptom management options are captured on state POLST forms

- **Title**: *Variations in Physician Order for Life-Sustaining Treatment (POLST) program across the nation: Environmental Scan*

- **Findings**
  - Total 50 U.S. states and Washington D.C. included in analysis
  - Mature status (n = 3), Endorsed (n = 20), Developing (n = 24), Non-Conforming (n =4)
  - Antibiotics option assessed on 32 forms (71%), IV fluid option assessed on 33 forms (77%)
  - Hospital transfer, Medication administration and Oxygen use assessed on all forms (100%)

Study 3

Aim: Controlling for other contextual and individual characteristics, examine impacts of POLST maturity status on the place of death (i.e., Nursing Home death) among elderly individuals residing in U.S. nursing homes

- **Title**: *Higher Maturity Status of Physician Orders for Life-Sustatining Treatment (POLST) and Greater Likelihood of Dying in Nursing Homes Among Long-Stay Residents*

- **Methods**: Multivariate logistic regression with clustering at county level

- **Findings**
  - Long-stay residents living in states where the POLST program was mature had 20% increased odds of dying in NHs (OR: 1.20; 95% CI 1.02-1.43) compared to non-conforming status
  - Endorsed or developing POLST status increased odds of dying in NHs (OR: 1.09; 95% CI 0.98-1.21 endorsed status; OR: 1.12; 95% CI 1.02-1.24 developing status)
  - No significant difference was noted among short-stay residents

Study Findings and Implications for Policy, Clinical Practice and Future Research

Our study findings reflect that the POLST program is generally effective in ensuring goal-concordant care at EoL, and the implementation of state-wide POLST program is associated with positive likelihood of NH death. However, the most variations observed in concordant care was in antibiotics use. It was not surprising that our findings generated from the POLST program environmental scan also indicated that the patient preference for antibiotics usage was the least frequently mentioned option, of all available POLST forms we examined.

Based on the previous finding, as high as 75% of NH residents are exposed to inappropriate antibiotics and many therapies are initiated against the patient's own wish,[22-25] it is important that there be a national, or facility-level policy to reinforce a timely assessment of EoL care preferences among seriously ill patients. In NH settings, this system can be incorporated as a part of MDS assessment, which can provide further benefit: a routine (quarterly) assessment.

As of 2019, California is the only state where the MDS assessment contains a separate section, section S (shown in **figure 6**), that prompts an assessment of whether the NH resident has a California POLST form completed and placed in chart.[26] While California is abiding to the POLST program requirement (i.e., the POLST form completion must remain voluntary),[19] eliciting the presence of the POLST form became a routine part of NH resident assessments. Implementing a similar system can provide a critical opportunity where further information on the POLST program be provided, and subsequent conversations regarding EoL care be held in timely fashion.

In existing studies, researchers identified two important provider-related barriers to the use of ACP tools and EoL care discussions: unfamiliarity with different ACP tools and lack of knowledge/ training in EoL conversation.[27-31] While research evidence for the positive impacts of ACP on patient outcomes are accumulating,[32-35] little is known the ways we can meet

educational needs of care providers. As lack of competency and little trainings would hinder translation of scientific knowledge to daily practices, it is important that we explore opportunities to train clinical staff, who would then serve as key persons in promoting quality EoL care.

Future Research Directions

Continued research efforts to identify the impact of the POLST program on diverse patient populations (i.e., young adults, ethnic minorities and homecare patients) and their caregivers can strengthen further dissemination of the POLST program. Furthermore, there is a lack of knowledge on the economic benefits of POLST program implementation in healthcare settings. Although it has been reported that the POLST program may reduce burdensome care transfers between NHs and emergency room/ intensive care use, cost-savings and economic benefits of POLST initiation within care facilities remain unknown.

Strengths and Limitations

Studies included in this dissertation implemented different research methods to explore outcomes of the POLST program. Our systematic review, which was guided by Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist, generated generalizable research findings by broadening eligibility criteria. In a previously published systematic review, the authors limited their study selection to institutional settings (i.e., hospitals, hospices and NHs). However, we noted that many of the POLST program users are residing in community care settings,[36,73] and that degrees in which POLST wishes are respected by emergency care responders were scarce.[274] Therefore, we expanded our study inclusion to the studies that examined the patient outcomes regardless of their care settings. As a result, we not only were able to generate updated findings on effectiveness of the POLST participation on receipt of preferred care, but also provided more generalizable findings.

In our environmental scan study, we developed a data collection tool and extracted relevant information that appeared on the most recent copy of state-level POLST forms. This provided a valuable opportunity to highlight similarities and differences in type of EoL care options that are currently captured on POLST forms and offered a comprehensive examination of areas that may warrant further examination such as those that can strengthen inter-state transferability of care wishes and standardization of the POLST form.

By using multiple large datasets in our quantitative study, and by incorporating our primary dataset (collected during our environmental study), we utilized scientifically rigorous methodology to examine the impacts of the POLST program maturity status on U.S. NH residents' care outcomes. In addition, our nationally representative study sample enhanced the generalizability of our study findings. County-level clustering, which accounted for repeated measures of unique NH facilities, added robustness to our study outcome estimates.

Nonetheless, we acknowledge that there are several limitations. In our systematic review conducted in chapter 2, it is possible that relevant research findings were missed due to issues related to: exclusion of grey literature; or exclusion criterion on the language or study types. Due to the tendency that studies reporting significant findings are more likely to be published than those without significant findings (i.e., publication bias) it is possible that we missed important study findings relevant to our research question. In addition, we limited our literature search to articles that were written in English language only, and quantitative research designs, and published in peer-reviewed journals. With such criteria, it is possible that we may have missed findings that may/ may not align with results we reported.

In both chapters 3 and 4, we did not include potential measures that can be indicative of actual POLST program usage among target population (e.g., number of POLST forms completed

per facility/state, and/or POLST forms submitted through state e-registry). Although it would have been ideal to include such information to generate more comprehensive research findings, we felt it remained out of scope of this dissertation. By failing to consider other measures than the maturity status as the level of program advancement, we may have inadvertently over-estimated the potential impact of the state's POLST maturity status on place of death. When interpreting our study results identified in both chapters 3 and 4, it should be taken into consideration that due to cross sectional study design implemented, our findings does not show causation, but only the association.

In the large datasets utilized for our multivariate regression model, covered in chapter 4, specific locations of patient death beyond NHs were not identified. Although we considered alternative measures (i.e., using *community* discharge prior to death as indication of death occurred at home) there was insufficient scientific evidence to conclude that *community* setting can serve as surrogate measure to one's own residence. Similarly, we were unable to determine if non-NH death captured in our study sample was related to specific patient requests to be transported to non-NH care settings. It was probable that those who died in non-NHs had specifically requested for a care transfer, or a care transfer at EoL was needed to enhance comfort of a dying patient. Either cases represent a high-level of patient-centered EoL care delivery and should be looked at as the best practices that increased care concordance.

Conclusion

The POLST program provides an important opportunity to facilitate EoL care discussions that reflect a dying patient's care wishes. It is an ACP tool that shows a high concordant rate between care that one wishes to receive, and actual care delivered at EoL. Since it was introduced to the public in early 1990s, the POLST program has been widely adopted in various healthcare settings (e.g., hospitals and NHs) and continues to be actively disseminated

throughout the nation. The positive association observed between the higher POLST maturity status and a higher likelihood of dying in NH facilities among long-stay NH residents is promising in that the POLST program can promote positive changes in the outcomes of EoL patients, most likely through spill-over effects.

Findings reported in this dissertation can serve as evidence-based guidance that supports the importance of delivering high-quality EoL among those who are living with advanced illnesses and/or chronic conditions. Increased awareness on the importance of ACP, and the positive outcomes associated with the use of POLST program can also help transform the culture of EoL care; from excessive use of interventions causing protracted death and dying, to the delivery of care that ensures a dying patient's basic human right – autonomy.


State of California-Health and Human Services Agency
California Department of Public Health

Section S
California

Resident
Identifier
Date

California POLST

S9040A
Does resident have a California POLST form in chart?
Select Code

S9040B
CA - Item selected in California POLST Section-A
Select Code

S9040C1
CA - Item selected in California POLST Section-B
Select Code

S9040D1
CA - Item selected in California POLST Section-C
Select Code

S9040E
CA-POLST Section D - Signature of Physician, Nurse Practitioner or Physician Assistant
Select Code

S9040F
CA - POLST D - Signature by Patient or Decision-maker
Select Code

S9040G
Discussed with in California POLST Section D
Select Code

S9040H
California POLST Section D - Advance Directive
Select Code

CDPH 310 (8/17)
MDS 3.0 October 2017

Figure 6. California MDS 3.0, section S

References

1. Beard JR, Bloom DE. Towards a comprehensive public health response to population ageing. *Lancet.* 2015;385(9968):658-661.
2. United States Census Bureau. Older People Projected to Outnumber Children for First Time in U.S. History. 2013; https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html. Accessed December 24, 2018.
3. Ortman JM, Velkoff, Victoria A., Hogan, Howard. An Aging Nation: The Older Population in the United States. In: U.S. Census Bureau, ed. *Current Population Reports.* Vol 2019. Wahington, DC.2014:25-1140.
4. Reher DS. Baby booms, busts, and population ageing in the developed world. *Population Studies.* 2015;69(sup1):S57-S68.
5. Castle SC, Uyemura K, Fulop T, Makinodan T. Host Resistance and Immune Responses in Advanced Age. *Clinics in Geriatric Medicine.* 2007;23(3):463-479.
6. Centers for Disease Control and Prevention. Get smart: know when antibiotics work in doctor's offices. 2006; https://www.cdc.gov/antibiotic-use/community/index.html. Accessed March 19, 2019.
7. Suzman R, Beard, J. Global health and aging: preface. 2011; www.nia.nih.gov/research/publication/global-health-and-aging/preface. Accessed April 1, 2019.
8. McPhail SM. Multimorbidity in chronic disease: impact on health care resources and costs. *Risk management and healthcare policy.* 2016;9:143-156.
9. Tinetti ME, Fried TR, Boyd CM. Designing health care for the most common chronic condition--multimorbidity. *Jama.* 2012;307(23):2493-2494.
10. Bluethmann SM, Mariotto AB, Rowland JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. 2016;25(7):1029-1036.
11. Rizzuto D, Melis RJF, Angleman S, Qiu C, Marengoni A. Effect of Chronic Diseases and Multimorbidity on Survival and Functioning in Elderly Adults. *Journal of the American Geriatrics Society.* 2017;65(5):1056-1060.
12. Marik PE. The Cost of Inappropriate Care at the End of life: Implications for an Aging Population. *American Journal of Hospice and Palliative Medicine®.* 2014;32(7):703-708.
13. Lupu D. The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up? *Journal of pain and symptom management.*55(4):1216-1223.
14. Pizzo PA. Thoughts about Dying in America: Enhancing the impact of one's life journey and legacy by also planning for the end of life. 2016;113(46):12908-12912.
15. Dying in America: improving quality and honoring individual preferences near the end of life. *Mil Med.* 2015;180(4):365-367.
16. National POLST Paradigm. In. Vol 2018.
17. Meier DE, Beresford L. POLST offers next stage in honoring patient preferences. *J Palliat Med.* 2009;12(4):291-295.
18. National POLST paradigm. History. 2019; https://polst.org/about-the-national-polst-paradigm/history/. Accessed December 12, 2018.
19. National POLST paradigm. POLST Paradigm Fundamentals. 2019; https://polst.org/about-the-national-polst-paradigm/what-is-polst/. Accessed January 3, 2019.
20. Zive DM, Schmidt TA. Pathways to POLST Registry Development: Lessons Learned. In: Tolle SW, ed. Portland, OR: Center for Ethics in Health Care Oregon Health & Science University; 2012: https://polst.org/wp-content/uploads/2012/12/POLST-Registry.pdf. Accessed January 3.
21. Hickman SE, Keevern E, Hammes BJ. Use of the physician orders for life-sustaining treatment program in the clinical setting: a systematic review of the literature. *Journal of the American Geriatrics Society.* 2015;63(2):341-350.

22. Jump RLP, Gaur S, Katz MJ, et al. Template for an Antibiotic Stewardship Policy for Post-Acute and Long-Term Care Settings. *Journal of the American Medical Directors Association.* 2017;18(11):913-920.
23. Pulia M, Kern M, Schwei RJ, Shah MN, Sampene E, Crnich CJ. Comparing appropriateness of antibiotics for nursing home residents by setting of prescription initiation: a cross-sectional analysis. *Antimicrobial resistance and infection control.* 2018;7:74-74.
24. Daneman N, Gruneir A, Newman A, et al. Antibiotic use in long-term care facilities. *The Journal of antimicrobial chemotherapy.* 2011;66(12):2856-2863.
25. Rhee SM, Stone ND. Antimicrobial stewardship in long-term care facilities. *Infectious disease clinics of North America.* 2014;28(2):237-246.
26. Smith KL. Minimum Data Set (MDS) 3.0 "Section S" and the Physician Orders for Life Sustaining Treatment (POLST). In: Health CDoP, ed. www.cdph.ca.gov: Center for Health Care Quality; 2010.
27. Ottoboni G, Chattat R, Camedda C, et al. Nursing home staff members' knowledge, experience and attitudes regarding advance care planning: a cross-sectional study involving 12 Italian nursing homes. *Aging Clinical and Experimental Research.* 2019.
28. Lum HD. Advance care planning in the elderly. *The Medical clinics of North America.*99(2):391-403.
29. Moore L. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian journal of caring sciences.*31(4):662-673.
30. Feraco AM. Communication Skills Training in Pediatric Oncology: Moving Beyond Role Modeling Communication in Pediatric Oncology. *Pediatric blood & cancer.*63(6):966-972.
31. Ke L-S. Nurses' views regarding implementing advance care planning for older people: a systematic review and synthesis of qualitative studies. *Journal of clinical nursing.*24(15-16):2057-2073.
32. Bond WF, Kim M, Franciskovich CM, et al. Advance Care Planning in an Accountable Care Organization Is Associated with Increased Advanced Directive Documentation and Decreased Costs. *Journal of Palliative Medicine.* 2017;21(4):489-502.
33. Mullick A, Martin J, Sallnow L. An introduction to advance care planning in practice. *BMJ : British Medical Journal.* 2013;347:f6064.
34. Dixon J, Karagiannidou M, Knapp M. The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers: A Systematic Review and Critical Discussion. *Journal of Pain and Symptom Management.* 2018;55(1):132-150.e131.
35. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ.* 2010;340:c1345.
36. Schmidt TA, Zive D, Fromme EK, Cook JNB, Tolle SW. Physician Orders for Life-Sustaining Treatment (POLST): Lessons learned from analysis of the Oregon POLST Registry. *Resuscitation.* 2014;85(4):480-485.
37. Henson LA, Gomes B, Koffman J, et al. Factors associated with aggressive end of life cancer care. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer.* 2016;24(3):1079-1089.
38. Cappell K, Sundaram V, Park A, et al. Advance Directive Utilization Is Associated with Less Aggressive End-of-Life Care in Patients Undergoing Allogeneic Hematopoietic Cell Transplantation. *Biology of Blood and Marrow Transplantation.* 2018;24(5):1035-1040.
39. Oczkowski SJW, Chung H-O, Hanvey L, Mbuagbaw L, You JJ. Communication tools for end-of-life decision-making in the intensive care unit: a systematic review and meta-analysis. *Critical Care.* 2016;20(1):97.
40. Lyon ME, Jacobs S, Briggs L, Cheng YI, Wang J. Family-Centered Advance Care Planning for Teens With CancerACP for Teens With Cancer. *JAMA Pediatrics.* 2013;167(5):460-467.
41. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med.* 2014;28(8):1000-1025.

42. Fried TR, Bullock K, Iannone L, O'Leary JR. Understanding advance care planning as a process of health behavior change. *Journal of the American Geriatrics Society.* 2009;57(9):1547-1555.
43. Kass-Bartelmes BL, Hughes R. Advance Care Planning. *Journal of Pain & Palliative Care Pharmacotherapy.* 2004;18(1):87-109.
44. Fagerlin A, Ditto PH, Hawkins NA, Schneider CE, Smucker WD. The Use of Advance Directives in End-of-life Decision Making: Problems and Possibilities. *American Behavioral Scientist.* 2002;46(2):268-283.
45. Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Cent Rep.* 2004;34(2):30-42.
46. Simon A. Historical Review of Advance Directives. In: Lack P, Biller-Andorno N, Brauer S, eds. *Advance Directives.* Dordrecht: Springer Netherlands; 2014:3-16.
47. Vogelstein E. Autonomy and the Moral Authority of Advance Directives. *J Med Philos.* 2016;41(5):500-520.
48. Emanuel EJ, Weinberg DS, Gonin R, Hummel LR, Emanuel LL. How well is the Patient Self-Determination Act working?: an early assessment. *Am J Med.* 1993;95(6):619-628.
49. Kelley K. The Patient Self-Determination Act. A matter of life and death. *Physician Assist.* 1995;19(3):49, 53-46, 59-60 passim.
50. Kossman DA. Prevalence, Views, and Impact of Advance Directives Among Older Adults. *Journal of gerontological nursing.*40(7):44-50.
51. Danis M. Following Advance Directives. *The Hastings Center report.*24(6).
52. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med.* 2010;362(13):1211-1218.
53. Greco PJ, Schulman KA, Lavizzo-Mourey R, Hansen-Flaschen J. The Patient Self-Determination Act and the future of advance directives. *Ann Intern Med.* 1991;115(8):639-643.
54. Perkins HS. Controlling death: the false promise of advance directives. *Ann Intern Med.* 2007;147(1):51-57.
55. Rao JK, Anderson LA, Lin F-C, Laux JP. Completion of advance directives among U.S. consumers. *American journal of preventive medicine.* 2014;46(1):65-70.
56. De Vleminck A, Pardon K, Houttekier D, Van den Block L, Vander Stichele R, Deliens L. The prevalence in the general population of advance directives on euthanasia and discussion of end-of-life wishes: a nationwide survey. *BMC palliative care.* 2015;14:71-71.
57. Salmond SW, David E. Attitudes toward advance directives and advance directive completion rates. *Orthop Nurs.* 2005;24(2):117-127; quiz 128-119.
58. Yadav KN, Gabler NB, Cooney E, et al. Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care. *Health Affairs.* 2017;36(7):1244-1251.
59. Braun KL, Onaka AT, Horiuchi BY. Advance Directive Completion Rates and End-of-Life Preferences in Hawaii. *Journal of the American Geriatrics Society.* 2001;49(12):1708-1713.
60. Danis M, Southerland LI, Garrett JM, et al. A Prospective Study of Advance Directives for Life-Sustaining Care. 1991;324(13):882-888.
61. Cox DM, Sachs GA. Advance Directives and The Patient Self-determination Act. *Clinics in Geriatric Medicine.* 1994;10(3):431-443.
62. Vearrier L. Failure of the Current Advance Care Planning Paradigm: Advocating for a Communications-Based Approach. *HEC forum : an interdisciplinary journal on hospitals' ethical and legal issues.* 2016;28(4):339-354.
63. Brett. Limitations of listing specific medical interventions in advance directives. *JAMA : the journal of the American Medical Association.* 1991;266(6).
64. Degrazia D. Advance Directives, Dementia, and 'The Someone Else Problem'. 1999;13(5):373-391.
65. Sabatino CP. The evolution of health care advance planning law and policy. *The Milbank quarterly.* 2010;88(2):211-239.

66. National POLST paradigm. Program Regonition. http://polst.org/program-recognition/?pro¼1. Accessed Jan 12, 2019, 2019.
67. Oregon POLST. Oregon POLST History. https://oregonpolst.org/history. Accessed November 13, 2018.
68. Hickman SE, Nelson CA, Perrin NA, Moss AH, Hammes BJ, Tolle SW. A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program. 2010;58(7):1241-1248.
69. Dunn PM, Schmidt TA, Carley MM, Donius M, Weinstein MA, Dull VT. A Method to Communicate Patient Preferences About Medically Indicated Life-Sustaining Treatment in the Out-of-Hospital Setting. 1996;44(7):785-791.
70. Tolle SW. Care of the Dying: Clinical and Financial Lessons from the Oregon Experience. *Annals of Internal Medicine.* 1998;128(7):567-568.
71. Tark A, Agarwal M, Dick AW, Stone PW. Variations in Physician Orders for Life-Sustaining Treatment Program across the Nation: Environmental Scan. *J Palliat Med.* 2019.
72. Tolle SW, Tilden VP, Nelson CA, Dunn PM. A prospective study of the efficacy of the physician order form for life-sustaining treatment. *J Am Geriatr Soc.* 1998;46(9):1097-1102.
73. Lee MA, Brummel-Smith K, Meyer J, Drew N, London MR. Physician orders for life-sustaining treatment (POLST): outcomes in a PACE program. Program of All-Inclusive Care for the Elderly. *J Am Geriatr Soc.* 2000;48(10):1219-1225.
74. Tolle SW, Tilden VP. Changing end-of-life planning: the Oregon experience. *J Palliat Med.* 2002;5(2):311-317.
75. Schmidt TA, Hickman SE, Tolle SW. Honoring treatment preferences near the end of life: the oregon physician orders for life-sustaining treatment (POLST) program. *Adv Exp Med Biol.* 2004;550:255-262.
76. The Office of the National Coordinator for Health Information Technology. Electronic End-of-Life and Physician Orders for Life-Sustaining Treatment (POLST) Documentation Access through Health Information Exchange (HIE). In:2018.
77. Dwyer R, Stoelwinder J, Gabbe B, Lowthian J. Unplanned Transfer to Emergency Departments for Frail Elderly Residents of Aged Care Facilities: A Review of Patient and Organizational Factors. *Journal of the American Medical Directors Association.* 2015;16(7):551-562.
78. Payne RA, Abel GA, Guthrie B, Mercer SW. The effect of physical multimorbidity, mental health conditions and socioeconomic deprivation on unplanned admissions to hospital: a retrospective cohort study. 2013;185(5):E221-E228.
79. Schmidt TA, Hickman SE, Tolle SW. Honoring treatment preferences near the end of life: The Oregon Physician Orders for Life-Sustaining Treatment (POLST) program. In. Vol 5502004:255-262.
80. Family Assets. The Difference Between Skilled Nursing and Nursing Home Care. 2018; https://www.familyassets.com/nursing-homes/resources/skilled-nursing-vs-nursing-home. Accessed November 11, 2018.
81. National Institute on Aging. What Is Long-Term Care? *Health Information* 2018; t. Accessed December 10, 2018.
82. Costantino M, Rees J. Rising Demand for Long-Term Services and Supports for Elderly People. In: Office CB, ed. cbo.gov: Congressional Budget Office; 2013.
83. Jones AL, Dwyer LL, Bercovitz AR, Strahan GW. The National Nursing Home Survey: 2004 overview. *Vital Health Stat 13.* 2009(167):1-155.
84. Centers for Disease Control and Prevention. Long-term care providers and services users in the United States: Data from the National Study of Long-Term Care Providers, 2013–2014. In: Services USDoHaH, ed. Vol 32016.
85. Safarpour D, Thibault DP, DeSanto CL, et al. Nursing home and end-of-life care in Parkinson disease. *Neurology.* 2015;85(5):413-419.

86. Gaugler JE, Yu F, Davila HW, Shippee T. Alzheimer's disease and nursing homes. *Health affairs (Project Hope).* 2014;33(4):650-657.
87. Buchanan RJ, Wang S, Huang C, Simpson P, Manyam BV. Analyses of nursing home residents with Parkinson's disease using the minimum data set. *Parkinsonism & Related Disorders.* 2002;8(5):369-380.
88. Stephens CE, Hunt LJ, Bui N, Halifax E, Ritchie CS, Lee SJ. Palliative care eligibility, symptom burden, and quality-of-life ratings in nursing home residents. *JAMA Internal Medicine.* 2018;178(1):141-142.
89. Hanson LC, Eckert JK, Dobbs D, et al. Symptom Experience of Dying Long-Term Care Residents. 2008;56(1):91-98.
90. Lester PE, Stefanacci RG, Feuerman M. Prevalence and Description of Palliative Care in US Nursing Homes: A Descriptive Study. *Am J Hosp Palliat Care.* 2016;33(2):171-177.
91. Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med.* 2011;365(13):1212-1221.
92. Aaltonen M, Raitanen J, Forma L, Pulkki J, Rissanen P, Jylha M. Burdensome transitions at the end of life among long-term care residents with dementia. *J Am Med Dir Assoc.* 2014;15(9):643-648.
93. Ruth PL, L. MS, L. GJ. Preventing Burdensome Transitions of Nursing Home Residents with Advanced Dementia: It's More than Advance Directives. 2017;20(11):1205-1209.
94. Institute of Medicine. Dying in America: Improving quality and honoring individual preferences near the end of life. In. Washington, DC: National Academies Press; 2014.
95. Medicine Io. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press; 2015.
96. Juthani-Mehta M, Malani PN, Mitchell SL. Antimicrobials at the End of Life: An Opportunity to Improve Palliative Care and Infection Management. *JAMA.* 2015;314(19):2017-2018.
97. Werner H, Kuntsche J. [Infection in the elderly--what is different?]. *Z Gerontol Geriatr.* 2000;33(5):350-356.
98. Norman DC, Yoshikawa TT. Fever in the elderly. *Infect Dis Clin North Am.* 1996;10(1):93-99.
99. Norman DC. Fever in the Elderly. *Clinical Infectious Diseases.* 2000;31(1):148-151.
100. Phillips CD. Asymptomatic bacteriuria, antibiotic use, and suspected urinary tract infections in four nursing homes. *BMC geriatrics.*12(1).
101. Agata ED, Loeb MB, Mitchell SL. Challenges in Assessing Nursing Home Residents with Advanced Dementia for Suspected Urinary Tract Infections. 2013;61(1):62-66.
102. Givens JL, Selby K, Goldfeld KS, Mitchell SL. Hospital transfers of nursing home residents with advanced dementia. *J Am Geriatr Soc.* 2012;60(5):905-909.
103. IRVINE PW, VAN BUREN N, CROSSLEY K. Causes for Hospitalization of Nursing Home Residents: The Role of Infection. 1984;32(2):103-107.
104. Yoshikawa TT, Norman DC. Approach to Fever and Infection in the Nursing Home. 1996;44(1):74-82.
105. Aaltonen M, Raitanen J, Forma L, Pulkki J, Rissanen P, Jylhä M. Burdensome Transitions at the End of Life Among Long-Term Care Residents With Dementia. *Journal of the American Medical Directors Association.* 2014;15(9):643-648.
106. Lamberg JL, Person CJ, Kiely DK, Mitchell SL. Decisions to Hospitalize Nursing Home Residents Dying with Advanced Dementia. 2005;53(8):1396-1401.
107. Bottrell MM, O'Sullivan JF, Robbins MA, Mitty EL, Mezey MD. Transferring dying nursing home residents to the hospital: DON perspectives on the nurse's role in transfer decisions. *Geriatric Nursing.* 2001;22(6):313-317.
108. Perrin A, Tavassoli N, Mathieu C, et al. Factors predisposing nursing home resident to inappropriate transfer to emergency department. The FINE study protocol. *Contemporary Clinical Trials Communications.* 2017;7:217-223.

109. Hickman SE, Tolle SW, Brummel-Smith K, Carley MM. Use of the Physician Orders for Life-Sustaining Treatment program in Oregon nursing facilities: beyond resuscitation status. *J Am Geriatr Soc.* 2004;52(9):1424-1429.
110. Hickman SE, Keevern E, Hammes BJ. Use of the Physician Orders for Life-Sustaining Treatment Program in the Clinical Setting: A Systematic Review of the Literature. 2015;63(2):341-350.
111. E. HS, Rebecca C. National Standards and State Variation in Physician Orders for Life-Sustaining Treatment Forms. 2018;21(7):978-986.
112. Zheng NT, Mukamel DB, Caprio TV, Temkin-Greener H. Hospice Utilization in Nursing Homes: Association With Facility End-of-Life Care Practices. *The Gerontologist.* 2012;53(5):817-827.
113. Zheng NT, Mukamel DB, Friedman B, Caprio TV, Temkin-Greener H. The effect of hospice on hospitalizations of nursing home residents. *Journal of the American Medical Directors Association.* 2015;16(2):155-159.
114. Miller SC, Mor V, Wu N, Gozalo P, Lapane K. Does receipt of hospice care in nursing homes improve the management of pain at the end of life? *J Am Geriatr Soc.* 2002;50(3):507-515.
115. Miller SC, Mor VNT. The role of hospice care in the nursing home setting. *Journal of palliative medicine.* 2002;5(2):271-277.
116. De Roo ML, Miccinesi G, Onwuteaka-Philipsen BD, et al. Actual and Preferred Place of Death of Home-Dwelling Patients in Four European Countries: Making Sense of Quality Indicators. *PLOS ONE.* 2014;9(4):e93762.
117. Howell DA, Wang HI, Roman E, et al. Preferred and actual place of death in haematological malignancy. *BMJ Support Palliat Care.* 2017;7(2):150-157.
118. Mukamel DB, Caprio T, Ahn R, et al. End-of-Life Quality-of-Care Measures for Nursing Homes: Place of Death and Hospice. *Journal of Palliative Medicine.* 2012;15(4):438-446.
119. Perrels AJ, Fleming J, Zhao J, et al. Place of death and end-of-life transitions experienced by very old people with differing cognitive status: Retrospective analysis of a prospective population-based cohort aged 85 and over. *Palliative medicine.* 2013;28(3):220-233.
120. Rainsford S, MacLeod RD, Glasgow NJ. Place of death in rural palliative care: A systematic review. *Palliat Med.* 2016;30(8):745-763.
121. Cardona-Morrell M, Kim JCH, Brabrand M, Gallego-Luxan B, Hillman K. What is inappropriate hospital use for elderly people near the end of life? A systematic review. *Eur J Intern Med.* 2017;42:39-50.
122. Houttekier D, Vandervoort A, Van den Block L, van der Steen JT, Vander Stichele R, Deliens L. Hospitalizations of nursing home residents with dementia in the last month of life: results from a nationwide survey. *Palliat Med.* 2014;28(9):1110-1117.
123. Menec VH, Nowicki S, Blandford A, Veselyuk D. Hospitalizations at the end of life among long-term care residents. *J Gerontol A Biol Sci Med Sci.* 2009;64(3):395-402.
124. Miller SC, Gozalo P, Mor V. Hospice enrollment and hospitalization of dying nursing home patients. *Am J Med.* 2001;111(1):38-44.
125. Gelberg L, Andersen RM, Leake BD. The Behavioral Model for Vulnerable Populations: application to medical care use and outcomes for homeless people. *Health services research.* 2000;34(6):1273-1302.
126. Andersen RM. Revisiting the Behavioral Model and Access to Medical Care: Does it Matter? *Journal of Health and Social Behavior.* 1995;36(1):1-10.
127. Aday LA, Awe WC. *Health services utilization models, in Handbook of Health Behavior Research I.* Vol 1. Plenum, New York1997.
128. Andersen RM. National health surveys and the behavioral model of health services use. *Med Care.* 2008;46(7):647-653.
129. Andersen RM. *Families' use of health services: a behavioral model of predisposing, enabling, and need componets* [Dissertation & Theses]. Ann Arbor: Sociology, Purdue University; 1968.
130. Saikia N, Moradhvaj, Bora JK. Gender Difference in Health-Care Expenditure: Evidence from India Human Development Survey. *PLOS ONE.* 2016;11(7):e0158332.

131. Al Snih S, Markides KS, Ray LA, Freeman JL, Ostir GV, Goodwin JS. Predictors of healthcare utilization among older Mexican Americans. *Ethn Dis.* 2006;16(3):640-646.
132. Parslow R, Jorm A, Christensen H, Jacomb P. Factors associated with young adults' obtaining general practitioner services. *Aust Health Rev.* 2002;25(6):109-118.
133. Dhingra SS, Zack M, Strine T, Pearson WS, Balluz L. Determining prevalence and correlates of psychiatric treatment with Andersen's behavioral model of health services use. *Psychiatr Serv.* 2010;61(5):524-528.
134. Devaux M. Income-related inequalities and inequities in health care services utilisation in 18 selected OECD countries. *The European Journal of Health Economics.* 2015;16(1):21-33.
135. Brown ER, Davidson PL, Yu H, et al. Effects of community factors on access to ambulatory care for lower-income adults in large urban communities. *Inquiry.* 2004;41(1):39-56.
136. Stockdale SE, Tang L, Zhang L, Belin TR, Wells KB. The effects of health sector market factors and vulnerable group membership on access to alcohol, drug, and mental health care. *Health Serv Res.* 2007;42(3 Pt 1):1020-1041.
137. Dummer TJB. Health geography: supporting public health policy and planning. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne.* 2008;178(9):1177-1180.
138. Adams WL, Yuan Z, Barboriak JJ, Rimm AA. Alcohol-Related Hospitalizations of Elderly People: Prevalence and Geographic Variation in the United States. *JAMA.* 1993;270(10):1222-1225.
139. Busby J, Purdy S, Hollingworth W. A systematic review of the magnitude and cause of geographic variation in unplanned hospital admission rates and length of stay for ambulatory care sensitive conditions. *BMC Health Services Research.* 2015;15(1):324.
140. Kolte D, Khera S, Aronow Wilbert S, et al. Regional Variation in the Incidence and Outcomes of In-Hospital Cardiac Arrest in the United States. *Circulation.* 2015;131(16):1415-1425.
141. Temkin-Greener H, Zheng NT, Mukamel DB. Rural–Urban Differences in End-of-Life Nursing Home Care: Facility and Environmental Factors. *The Gerontologist.* 2012;52(3):335-344.
142. Mackenzie CS, Pagura J, Sareen J. Correlates of perceived need for and use of mental health services by older adults in the collaborative psychiatric epidemiology surveys. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry.* 2010;18(12):1103-1115.
143. Garrido MM, Kane RL, Kaas M, Kane RA. Use of mental health care by community-dwelling older adults. *J Am Geriatr Soc.* 2011;59(1):50-56.
144. Byers AL, Arean PA, Yaffe K. Low use of mental health services among older Americans with mood and anxiety disorders. *Psychiatr Serv.* 2012;63(1):66-72.
145. Li Y-N, Nong D-x, Wei B, Feng Q-M, Luo H-y. The impact of predisposing, enabling, and need factors in utilization of health services among rural residents in Guangxi, China. *BMC Health Services Research.* 2016;16(1):592.
146. Babitsch B, Gohl D, von Lengerke T. Re-revisiting Andersen's Behavioral Model of Health Services Use: a systematic review of studies from 1998-2011. *Psychosoc Med.* 2012;9:Doc11.
147. Brugger C, Breschi LC, Hart EM, et al. The POLST paradigm and form:Facts and analysis. *Linacre Q.* 2013;80(2):103-138.
148. Kim H, Ersek M, Bradway C, Hickman SE. Physician Orders for Life-Sustaining Treatment for nursing home residents with dementia. *Journal of the American Association of Nurse Practitioners.* 2015;27(11):606-614.
149. Hopping-Winn J, Mullin J, March L, Caughey M, Stern M, Jarvie J. The Progression of End-of-Life Wishes and Concordance with End-of-Life Care. *Journal of Palliative Medicine.* 2018;21(4):541-545.
150. Lum H, Obafemi O, Dukes J, Nowels M, Samon K, Boxer RS. Use of Medical Orders for Scope of Treatment for Heart Failure Patients During Postacute Care in Skilled Nursing Facilities. *Journal of the American Medical Directors Association.* 2017;18(10):885-890.

151. Moher D, Liberati A, Tetzlaff J, Altman DG, and the PG. Preferred reporting items for systematic reviews and meta-analyses: The prisma statement. *Annals of Internal Medicine*. 2009;151(4):264-269.
152. Luchini C, Stubbs B, Solmi M, Veronese N. Assessing the quality of studies in meat-analyses: Advantages and Limitations of the Newcastle Ottawa Scale. *World Journal of Meta-Analysis.* 2017;5(4):80-84.
153. Hootman JM, Driban JB, Sitler MR, Harris KP, Cattano NM. Reliability and validity of three quality rating instruments for systematic reviews of observational studies. *Res Synth Methods.* 2011;2(2):110-118.
154. Margulis AV, Pladevall M, Riera-Guardia N, et al. Quality assessment of observational studies in a drug-safety systematic review, comparison of two tools: the Newcastle-Ottawa Scale and the RTI item bank. *Clin Epidemiol.* 2014;6:359-368.
155. U.S Department of Health & Human Services. Methods Guide for Effectiveness and Comparative Effectiveness Reviews. 2014; www.effectivehealthcare.ahrq.gov. Accessed April 24, 2018.
156. Lee MA, Brummel-Smith K, Meyer J, Drew N, London MR. Physician Orders for Life-Sustaining Treatment (POLST): Outcomes in a PACE program. *Journal of the American Geriatrics Society.* 2000;48(10):1219-1225.
157. Hickman SE, Nelson CA, Moss AH, et al. Use of the physician orders for life-sustaining treatment (POLST) paradigm program in the hospice setting. *Journal of Palliative Medicine.* 2009;12(2):133-141.
158. Hickman SE, Nelson CA, Moss AH, Tolle SW, Perrin NA, Hammes BJ. The consistency between treatments provided to nursing facility residents and orders on the physician orders for life-sustaining treatment form. *Journal of the American Geriatrics Society.* 2011;59(11):2091-2099.
159. Schmidt TA, Olszewski EA, Zive D, Fromme EK, Tolle SW. The Oregon physician orders for life-sustaining treatment registry: a preliminary study of emergency medical services utilization. *J Emerg Med.* 2013;44(4):796-805.
160. Hammes BJ, Rooney BL, Gundrum JD, Hickman SE, Hager N. The POLST program: A retrospective review of the demographics of use and outcomes in one community where advance directives are prevalent. *Journal of Palliative Medicine.* 2012;15(1):77-85.
161. Richardson DK, Fromme E, Zive D, Fu R, Newgard CD. Concordance of out-of-hospital and emergency department cardiac arrest resuscitation with documented end-of-life choices in Oregon. *Annals of Emergency Medicine.* 2014;63(4):375-383.
162. Fromme EK, Zive D, Schmidt TA, et al. POLST Registry do-not-resuscitate orders and other patient treatment preferences. *JAMA: Journal of the American Medical Association.* 2012;307(1):34-35.
163. Klein J, Livergant JPI. Systematic Review of Factors Preventing Referral for Palliative Radiotherapy. *International Journal of Radiation Oncology • Biology • Physics.* 2017;99(2):E522-E523.
164. Kline KA, Bowdish DM. Infection in an aging population. *Curr Opin Microbiol.* 2016;29:63-67.
165. Kuswardhani RAT, Sugi YS. Factors Related to the Severity of Delirium in the Elderly Patients With Infection. *Gerontology and Geriatric Medicine.* 2017;3:2333721417739188.
166. Bowman CE, Elford J, Dovey J, Campbell S, Barrowclough H. Acute hospital admissions from nursing homes: some may be avoidable. *Postgraduate Medical Journal.* 2001;77(903):40-42.
167. Montoya A, Mody L. Common infections in nursing homes: a review of current issues and challenges. *Aging health.* 2011;7(6):889-899.
168. Tripken JL, Elrod C, Bills S. Factors Influencing Advance Care Planning Among Older Adults in Two Socioeconomically Diverse Living Communities. *Am J Hosp Palliat Care.* 2018;35(1):69-74.

169. U.S. Department of Health & Human Services. Electronic End-of-Life and Physician Orders for Life-Sustaining Treatment (POLST) Documentation Access through Health Information Exchange. In:2017.
170. Oregon POLST. Statement on Oregon POLST Separation from National POLST. 2018; https://static1.squarespace.com/static/52dc687be4b032209172e33e/t/5b05ff462b6a28e3e73cabac/1527119687088/2018.05.23+Statement+on+Oregon+POLST+separation+from+National+POLST.pdf. Accessed April 6, 2018.
171. National POLST Paradigm. POLST program status. 2018; http://polst.org/wp-content/uploads/2018/08/2018.04.11-POLST-Program-Status.pdf. Accessed May 21, 2018.
172. Anderson G. *Chronic care: making the case for ongoing care.* . Robert Wood Johnson Foundation;2010.
173. Tang ST. When death is imminent: where terminally ill patients with cancer prefer to die and why. *Cancer Nurs.* 2003;26(3):245-251.
174. Silveira MJ, Kim SYH, Langa KM. Advance Directives and Outcomes of Surrogate Decision Making before Death. *New England Journal of Medicine.* 2010;362(13):1211-1218.
175. Green MJ, Levi BH. Development of an interactive computer program for advance care planning. *Health Expectations.* 2009;12(1):60-69.
176. Robinson MK, DeHaven MJ, Koch KA. Effects of the Patient Self-Determination Act on patient knowledge and behavior. *J Fam Pract.* 1993;37(4):363-368.
177. Habal MV, Micevski V, Greenwood S, Delgado DH, Ross HJ. How aware of advanced care directives are heart failure patients, and are they using them? *Can J Cardiol.* 2011;27(3):376-381.
178. Hickey DP. The disutility of advance directives: we know the problems, but are there solutions? *J Health Law.* 2003;36(3):455-473.
179. Wenger NS, Citko J, O'Malley K, et al. Implementation of Physician Orders for Life Sustaining Treatment in Nursing Homes in California: Evaluation of a Novel Statewide Dissemination Mechanism. *Journal of General Internal Medicine.* 2013;28(1):51-57.
180. Sebastian P, Freitas B, Fischberg D. Provider Orders for Life-Sustaining Treatment Implementation and Training in Nursing Facilities in Hawai'i. *Hawai'i Journal of Medicine & Public Health.* 2015;74(9 Suppl 2):8-11.
181. Hickman SE, Sudore RL, Sachs GA, et al. Use of the Physician Orders for Scope of Treatment Program in Indiana Nursing Homes. *Journal of the American Geriatrics Society.* 2018;66(6):1096-1100.
182. Bierman M, Hadley J, Pendleton K, Garrison A. National POLST Paradigm. In: *Program Development Guide.*2015: http://polst.org/wp-content/uploads/2015/07/POLST-Program-Development-Guide.pdf/.
183. Moss AH, Zive DM, Falkenstine EC, Dunithan C. The Quality of POLST Completion to Guide Treatment: A 2-State Study. *J Am Med Dir Assoc.* 2017;18(9):810.e815-810.e819.
184. Fleiss JL. Measuring nominal scale agreement among many raters. *Psychological Bulletin.* 1971;76:378-382.
185. Bomba PA, Orem K. Lessons learned from New York's community approach to advance care planning and MOLAT. *Annals of palliative medicine.* 2015;4(1):10-21.
186. Fritz ZBM, Barclay SI. Patients' resuscitation preferences in context: Lessons from POLST. *Resuscitation.* 2014;85(4):444-445.
187. Schmidt TA, Zive D, Fromme EK, Cook JN, Tolle SW. Physician orders for life-sustaining treatment (POLST): lessons learned from analysis of the Oregon POLST Registry. *Resuscitation.* 2014;85(4):480-485.
188. Cardona-Morrell M, Kim JCH, Turner RM, Anstey M, Mitchell IA, Hillman K. Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem. *International Journal for Quality in Health Care.* 2016;28(4):456-469.

189. Teno JM, Gozalo PL, Bynum JPW, et al. Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009. *JAMA : the journal of the American Medical Association.* 2013;309(5):470-477.
190. Helde-Frankling M, Bergqvist J, Bergman P, Bjorkhem-Bergman L. Antibiotic Treatment in End-of-Life Cancer Patients-A Retrospective Observational Study at a Palliative Care Center in Sweden. *Cancers (Basel).* 2016;8(9).
191. Servid SA, Noble BN, Fromme EK, Furuno JP. Clinical Intentions of Antibiotics Prescribed Upon Discharge to Hospice Care. *J Am Geriatr Soc.* 2018;66(3):565-569.
192. Lam PT, Chan KS, Tse CY, Leung MW. Retrospective analysis of antibiotic use and survival in advanced cancer patients with infections. *J Pain Symptom Manage.* 2005;30(6):536-543.
193. Thompson AJ, Silveira MJ, Vitale CA, Malani PN. Antimicrobial use at the end of life among hospitalized patients with advanced cancer. *Am J Hosp Palliat Care.* 2012;29(8):599-603.
194. Leibovici L, Paul M, Ezra O. Ethical dilemmas in antibiotic treatment. *J Antimicrob Chemother.* 2012;67(1):12-16.
195. Harris-Kojetin L, Sengupta M, Park-Lee E, et al. Long-Term Care Providers and Services Users in the United States: Data From the National Study of Long-Term Care Providers, 2013–2014. In: Statistics NCfH, ed. Vol 3(38): Vital Health Stat; 2016.
196. Barbera L, Seow H, Sutradhar R, et al. Quality Indicators of End-of-Life Care in Patients With Cancer: What Rate Is Right? *Journal of oncology practice.* 2015;11(3):e279-287.
197. Houser A. Long-Term Care. In. AARP Public Policy Institute 2007.
198. De Roo ML, Miccinesi G, Onwuteaka-Philipsen BD, et al. Actual and preferred place of death of home-dwelling patients in four European countries: making sense of quality indicators. *PloS one.* 2014;9(4):e93762-e93762.
199. Miyashita M, Morita T, Ichikawa T, Sato K, Shima Y, Uchitomi Y. Quality Indicators of End-of-Life Cancer Care from the Bereaved Family Members' Perspective in Japan. *Journal of Pain and Symptom Management.* 2009;37(6):1019-1026.
200. Kelly A, Conell-Price J, Covinsky K, et al. Length of stay for older adults residing in nursing homes at the end of life. *Journal of the American Geriatrics Society.* 2010;58(9):1701-1706.
201. Day T. Guide to Long Term Care Planning. *About Nursing Homes* 2017; https://www.longtermcarelink.net/eldercare/nursing_home.htm. Accessed January 1, 2019.
202. Xue Q-L. The frailty syndrome: definition and natural history. *Clinics in geriatric medicine.* 2011;27(1):1-15.
203. Walston J, Hadley EC, Ferrucci L, et al. Research Agenda for Frailty in Older Adults: Toward a Better Understanding of Physiology and Etiology: Summary from the American Geriatrics Society/National Institute on Aging Research Conference on Frailty in Older Adults. *Journal of the American Geriatrics Society.* 2006;54(6):991-1001.
204. Institute of Medicine (US) and National Research Council (US) National Cancer Policy Board. *Quality of Care and Quality Indicators for End-of-Life Cancer Care: Hope for the Best, Yet Prepare for the Worst.* Vol 3. Washington (DC): National Academies Press (US); 2001.
205. Donaldson MS, Field MJ. Measuring Quality of Care at the End of Life. *Archives of Internal Medicine.* 1998;158(2):121-128.
206. Wenger NS, Rosenfeld K. Quality Indicators for End-of-Life Care in Vulnerable Elders. *Annals of Internal Medicine.* 2001;135(8_Part_2):677-685.
207. Silvester W. Development and evaluation of an aged care specific Advance Care Plan. *BMJ supportive & palliative care.*3(2):188-195.
208. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying Potential Indicators of the Quality of End-of-Life Cancer Care From Administrative Data. *Journal of Clinical Oncology.* 2003;21(6):1133-1138.
209. Temkin-Greener H, Zheng NT, Xing J, Mukamel DB. Site of death among nursing home residents in the United States: changing patterns, 2003-2007. *Journal of the American Medical Directors Association.* 2013;14(10):741-748.

210. Lepore M, Leland NE. Nursing Homes That Increased The Proportion Of Medicare Days Saw Gains In Quality Outcomes For Long-Stay Residents. *Health affairs (Project Hope).* 2015;34(12):2121-2128.
211. Ziegler LE, Craigs CL, West RM, et al. Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study. 2018;8(1):e018284.
212. Wattmo C, Wallin ÅK. Early- versus Late-Onset Alzheimer Disease: Long-Term Functional Outcomes, Nursing Home Placement, and Risk Factors for Rate of Progression. *Dementia and Geriatric Cognitive Disorders Extra.* 2017;7(1):172-187.
213. Safarpour D. Nursing home and end-of-life care in Parkinson disease. *Neurology.*85(5):413-419.
214. Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. Alzheimer disease in the US population: prevalence estimates using the 2000 census. *Archives of neurology.* 2003;60(8):1119-1122.
215. Lueckel SN. Population of Patients With Traumatic Brain Injury in Skilled Nursing Facilities: A Decade of Change. *The journal of head trauma rehabilitation.* 2019;34(1):E39-E45.
216. Jerez-Roig J. Prevalence of urinary incontinence and associated factors in nursing home residents Urinary Incontinence in Nursing Home Residents. *Neurourology and urodynamics.*35(1):102-107.
217. Gabbe B, Lowthian J, Dwyer R, Stoelwinder JU. A systematic review of outcomes following emergency transfer to hospital for residents of aged care facilities. *Age and Ageing.* 2014;43(6):759-766.
218. Laurent M, Bories PN, Le Thuaut A, et al. Impact of Comorbidities on Hospital-Acquired Infections in a Geriatric Rehabilitation Unit: Prospective Study of 252 Patients. *Journal of the American Medical Directors Association.* 2012;13(8):760.e767-760.e712.
219. Gruneir A, Mor V, Weitzen S, Truchil R, Teno J, Roy J. Where people die: a multilevel approach to understanding influences on site of death in America. *Medical care research and review : MCRR.* 2007;64(4):351-378.
220. Lamberg JL, Person CJ, Kiely DK, Mitchell SL. Decisions to hospitalize nursing home residents dying with advanced dementia. *J Am Geriatr Soc.* 2005;53(8):1396-1401.
221. Morley JE. Opening Pandora's Box: The Reasons Why Reducing Nursing Home Transfers to Hospital are so Difficult. *Journal of the American Medical Directors Association.* 2016;17(3):185-187.
222. van der Steen JT, Lemos Dekker N, Gijsberts M-JHE, Vermeulen LH, Mahler MM, The BA-M. Palliative care for people with dementia in the terminal phase: a mixed-methods qualitative study to inform service development. *BMC Palliative Care.* 2017;16(1):28.
223. Temkin-Greener H, Zheng NT, Norton SA, Quill T, Ladwig S, Veazie P. Measuring end-of-life care processes in nursing homes. *The Gerontologist.* 2009;49(6):803-815.
224. Saliba D, Kington R, Buchanan J, et al. Appropriateness of the decision to transfer nursing facility residents to the hospital. *J Am Geriatr Soc.* 2000;48(2):154-163.
225. Teno JM, Gozalo PL, Bynum JPW, et al. Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009End-of-Life Care for Medicare Beneficiaries. *JAMA.* 2013;309(5):470-477.
226. Fromme EK, Zive D, Schmidt TA, Cook JN, Tolle SW. Association between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and in-hospital death in Oregon. *J Am Geriatr Soc.* 2014;62(7):1246-1251.
227. Tuck KK, Zive DM, Schmidt TA, Carter J, Nutt J, Fromme EK. Life-sustaining treatment orders, location of death and co-morbid conditions in decedents with Parkinson's disease. *Parkinsonism & related disorders.* 2015;21(10):1205-1209.
228. Hickman SE. Use of the Physician Orders for Scope of Treatment Program in Indiana Nursing Homes Use of Indiana POST in Nursing Homes. *Journal of the American Geriatrics Society (JAGS).*66(6):1096-1100.

229. Kim H. Physician Orders for Life-Sustaining Treatment for nursing home residents with dementia. *Journal of the American Association of Nurse Practitioners.*27(11):606-614.
230. Committee on Approaching Death: Addressing Key End of Life I, Institute of M. In: *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.* Washington (DC): National Academies Press (US)

231. Knestrick MW, Pedraza SL, Culp S, Falkenstine EC, Moss AH. Benefits of physician orders for scope of treatment (POST) forms on end-of-life care in cancer patients: Insights from the West Virginia registry. *Journal of Clinical Oncology.* 2016;34(15_suppl):10006-10006.
232. Nugent SM, Slatore CG, Ganzini L, et al. POLST Registration and Associated Outcomes Among Veterans With Advanced-Stage Lung Cancer. *American Journal of Hospice and Palliative Medicine®.* 2019:1049909118824543.
233. Sebastian P. Healthcare Professionals' Perceptions and Use of the Provider Orders for Life-Sustaining Treatment (POLST) Form. *Journal of the American Medical Directors Association.*18(3):B22-B23.
234. Braun UK. Experiences with POLST: Opportunities for Improving Advance Care Planning. *Journal of General Internal Medicine.* 2016;31(10):1111-1112.
235. Morley JE. Minimum Data Set 3.0: a giant step forward. *Journal of the American Medical Directors Association.*14(1):1-3.
236. Saliba D, Buchanan J. Making the Investment Count: Revision of the Minimum Data Set for Nursing Homes, MDS 3.0. *Journal of the American Medical Directors Association.* 2012;13(7):602-610.
237. Wysocki A, Thomas KS, Mor V. Functional Improvement Among Short-Stay Nursing Home Residents in the MDS 3.0. *Journal of the American Medical Directors Association.* 2015;16(6):470-474.
238. Lucas JA, Bowblis JR. CMS Strategies To Reduce Antipsychotic Drug Use In Nursing Home Patients With Dementia Show Some Progress. *Health Aff (Millwood).* 2017;36(7):1299-1308.
239. Hunnicutt JN, Tjia J, Lapane KL. Hospice Use and Pain Management in Elderly Nursing Home Residents With Cancer. *Journal of Pain and Symptom Management.* 2017;53(3):561-570.
240. Dick AW, Bell JM, Stone ND, Chastain AM, Sorbero M, Stone PW. Nursing home adoption of the National Healthcare Safety Network Long-term Care Facility Component. *Am J Infect Control.* 2019;47(1):59-64.
241. Holup AA, Gassoumis ZD, Wilber KH, Hyer K. Community Discharge of Nursing Home Residents: The Role of Facility Characteristics. *Health services research.* 2016;51(2):645-666.
242. Centers for Medicare & Medicaid Services. Master Beneficiary Summary File (MBSF) LDS. 2018; https://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/LimitedDataSets/MBSF-LDS.html.
243. Miller SC, Lima JC, Intrator O, Martin E, Bull J, Hanson LC. Palliative Care Consultations in Nursing Homes and Reductions in Acute Care Use and Potentially Burdensome End-of-Life Transitions. 2016;64(11):2280-2287.
244. Phillips LJ, Birtley NM, Petroski GF, Siem C, Rantz M. An observational study of antipsychotic medication use among long-stay nursing home residents without qualifying diagnoses. 2018;25(8):463-474.
245. Jennifer T, Marisa D, L. GJ. Advance Directives among Nursing Home Residents with Mild, Moderate, and Advanced Dementia. 2018;21(1):16-21.
246. Stein JA, Andersen R, Gelberg L. Applying the Gelberg-Andersen Behavioral Model for Vulnerable Populations to Health Services Utilization in Homeless Women. *Journal of Health Psychology.* 2007;12(5):791-804.
247. Temkin-Greener H, Lee T, Caprio T, Cai S. Rehabilitation Therapy for Nursing Home Residents at the End-of-Life. *Journal of the American Medical Directors Association.* 2018.

248. Carpenter GI, Hastie CL, Morris JN, Fries BE, Ankri J. Measuring change in activities of daily living in nursing home residents with moderate to severe cognitive impairment. *BMC Geriatrics.* 2006;6(1):7.
249. Grabowski DC, Feng Z, Hirth R, Rahman M, Mor V. Effect of nursing home ownership on the quality of post-acute care: An instrumental variables approach. *Journal of Health Economics.* 2013;32(1):12-21.
250. Cohen CC, Engberg J, Herzig CTA, Dick AW, Stone PW. Nursing Homes in States with Infection Control Training or Infection Reporting Have Reduced Infection Control Deficiency Citations. *Infection Control & Hospital Epidemiology.* 2015;36(12):1475-1476.
251. Benjamin-Chung J, Abedin J, Berger D, et al. Spillover effects on health outcomes in low- and middle-income countries: a systematic review. *International journal of epidemiology.* 2017;46(4):1251-1276.
252. Nanda A, Martin EW, Welch LC, Miller SC. Referral and Timing of Referral to Hospice Care in Nursing Homes: The Significant Role of Staff Members. *The Gerontologist.* 2008;48(4):477-484.
253. Pearson ML, Wyte-Lake T, Bowman C, Needleman J, Dobalian A. Assessing the impact of academic-practice partnerships on nursing staff. *BMC Nursing.* 2015;14(1):28.
254. Sprangers S, Dijkstra K, Romijn-Luijten A. Communication skills training in a nursing home: effects of a brief intervention on residents and nursing aides. *Clinical interventions in aging.* 2015;10:311-319.
255. Miller SC, Lima JC, Thompson SA. End-of-Life Care in Nursing Homes with Greater versus Less Palliative Care Knowledge and Practice. *Journal of palliative medicine.* 2015;18(6):527-534.
256. Lebenthal J, Barile D, Sedhom R. Does use of the POLST form implicate overall care for patients with advanced cancer syndromes? *Journal of Clinical Oncology.* 2017;35(31_suppl):15-15.
257. Ballou JH, Dewey E, Zonies DH. Elderly Patients Presenting to a Level I Trauma Center with a POLST form: A Propensity-Matched Analysis. *The journal of trauma and acute care surgery.* 2019.
258. Guidelines for Emergency Physicians on the Interpretation of Physician Orders for Life-Sustaining Therapy (POLST). *Annals of emergency medicine.* 2017;70(1):122-125.
259. Lammers AJ, Zive DM, Tolle SW, Fromme EK. The Oncology Specialist's Role in POLST Form Completion. *The American journal of hospice & palliative care.* 2018;35(2):297-303.
260. Schmidt TA, Hickman SE, Tolle SW, Brooks HS. The Physician Orders for Life-Sustaining Treatment program: Oregon emergency medical technicians' practical experiences and attitudes. *J Am Geriatr Soc.* 2004;52(9):1430-1434.
261. Porock D, Oliver DP, Zweig S, et al. Predicting death in the nursing home: development and validation of the 6-month Minimum Data Set mortality risk index. *J Gerontol A Biol Sci Med Sci.* 2005;60(4):491-498.
262. Drageset J, Eide GE, Ranhoff AH. Mortality in nursing home residents without cognitive impairment and its relation to self-reported health-related quality of life, sociodemographic factors, illness variables and cancer diagnosis: a 5-year follow-up study. *Quality of Life Research.* 2013;22(2):317-325.
263. Van Rensbergen G, Nawrot TS, Van Hecke E, Nemery B. Where do the elderly die? The impact of nursing home utilisation on the place of death. Observations from a mortality cohort study in Flanders. *BMC Public Health.* 2006;6(1):178.
264. Vossius C, Selbæk G, Šaltytė Benth J, Bergh S. Mortality in nursing home residents: A longitudinal study over three years. *PLOS ONE.* 2018;13(9):e0203480.
265. Zhang X, Dou Q, Zhang W, et al. Frailty as a Predictor of All-Cause Mortality Among Older Nursing Home Residents: A Systematic Review and Meta-analysis. *Journal of the American Medical Directors Association.* 2019.
266. Hjaltadottir I, Hallberg IR, Ekwall AK, Nyberg P. Predicting mortality of residents at admission to nursing home: a longitudinal cohort study. *BMC Health Serv Res.* 2011;11:86.

267. Salomon S, Chuang E, Bhupali D, Labovitz D. Race/Ethnicity as a Predictor for Location of Death in Patients With Acute Neurovascular Events. *The American journal of hospice & palliative care.* 2018;35(1):100-103.
268. Kwak J, Haley WE, Chiriboga DA. Racial Differences in Hospice Use and In-Hospital Death Among Medicare and Medicaid Dual-Eligible Nursing Home Residents. *The Gerontologist.* 2008;48(1):32-41.
269. Sund-Levander M, Grodzinsky E, Wahren LK. Gender differences in predictors of survival in elderly nursing-home residents: a 3-year follow up. *Scandinavian Journal of Caring Sciences.* 2007;21(1):18-24.
270. Lapane KL, Gambassi G, Landi F, Sgadari A, Mor V, Bernabei R. Gender differences in predictors of mortality in nursing home residents with AD. *Neurology.* 2001;56(5):650.
271. Fernandez HH, Lapane KL. Predictors of mortality among nursing home residents with a diagnosis of Parkinson's disease. *Medical science monitor : international medical journal of experimental and clinical research.* 2002;8(4):Cr241-246.
272. Hoffmann F, Allers K. Age and sex differences in hospitalisation of nursing home residents: a systematic review. *BMJ Open.* 2016;6(10):e011912.
273. Lee JS, Chau PP, Hui E, Chan F, Woo J. Survival prediction in nursing home residents using the Minimum Data Set subscales: ADL Self-Performance Hierarchy, Cognitive Performance and the Changes in Health, End-stage disease and Symptoms and Signs scales. *Eur J Public Health.* 2009;19(3):308-312.
274. Zive DM, Schmidt TA. Pathways to POLST Registry Development: Lessons Learned. 2012.

Appendix A. Data Collection Tool used for the POLST Environmental Scan Study

POLST Environmental Study Data Collection Tool

Start of Block: Section 1 : POLST national program website scan

POLST ID

_____

STATE name:

_____

Data collector

_____

Date of form completion (MM/DD/YYYY)

_____

Page Break

Q1 Status level

- O Mature (1)
- O Endorsed (2)
- O Developing (3)
- O Non-conforming (4)
- O None (5)

Skip To: End of Survey If Status level = None

Q2 Program contact available?

- O Yes (1)
- O No (2)

Q3 Program name?

- O POLST (1)
- O Other (Please specify) (2) _____

Q4 Start year for the program (YYYY)

_____

Q5 Endorsed since (MM/DD/YYYY)

_____

Q6 Mature since (MM/DD/YYYY)

_____

Q7 Legislative information available?

O Yes (1)

O No (2)

Q8 Program website available?

O Yes (please provide URL) (1) _____

O Yes, website available BUT not functioning (2)

O No (3)

Skip To: End of Block If Program website available? = Yes, website available BUT not functioning

Skip To: End of Block If Program website available? = Yes, website available BUT not functioning

Skip To: End of Survey If Program website available? = No

Page Break

End of Block: Section 1 : POLST national program website scan

Start of Block: Section 2: State's POLST website scan

Q9 Does the POLST website offer Help-line / Contact number to ask questions?

- O Yes (1)
- O No (2)
- O Email only (3)

Q10 Able to view or print POLST form from the website?

- O Yes, able to view AND print (1)
- O Sample / voided form available to view or print (2)
- O No, sample form unavailable must request to see the form (3)
- O Link available, but not functioning (Error message) (4)
- O The website does not offer POLST form (5)

Skip To: End of Survey If Able to view or print POLST form from the website? = No, sample form unavailable must request to see the form

Skip To: End of Survey If Able to view or print POLST form from the website? = Link available, but not functioning (Error message)

Skip To: End of Survey If Able to view or print POLST form from the website? = The website does not offer POLST form

Q11 POLST registry available?

- O Yes (1)
- O No (2)

Skip To: Q13 If POLST registry available? = No

Q12 Able to upload a POLST form / search for a patient through registry?

- O Yes, able to upload a POLST form AND search for a patient through registry (1)
- O Able to upload a POLST form, only (2)
- O Able to search for a patient through registry, only (3)

Q13 Does the website offer additional information for patients or families?

- O Yes (1)
- O No (2)

Q14 Does the website offer additional information on POLST program? (e.g. Brochures, Educational Videos)

- O Yes (1)
- O No (2)

Skip To: Q16 If Does the website offer additional information on POLST program? (e.g. Brochures, Educational Vide... = No

---

Q15 Please select resources available from the website (select all that apply)

- ☐ Brochures on POLST program (1)
- ☐ Educational videos on POLST (2)
- ☐ FAQs on POLST program (3)

Q16 Does the website provide POLST form in different languages other than English?

O Yes (1)

O No (2)

Skip To: End of Block If Does the website provide POLST form in different languages other than English? = No

Q17 POLST form available in following languages? (Select all that apply)

- ☐ Chinese (Traditional) (1)
- ☐ Chinese (Simplified) (2)
- ☐ Farsi (3)
- ☐ Hmong (4)
- ☐ Japanese (5)
- ☐ Korean (6)
- ☐ Pashto (7)
- ☐ Russian (8)
- ☐ Spanish (9)
- ☐ Tagalog (10)
- ☐ Vietnamese (11)
- ☐ Braille (available to request) (12)
- ☐ Arabic (13)
- ☐ Portuguese (14)
- ☐ Haitian Creole (15)
- ☐ Khmer (16)
- ☐ Cape Verdean (17)

End of Block: Section 2: State's POLST website scan

Start of Block: Overview of POLST form

Overview 1 Does the POLST form have a separate section for Future Hospitalization and Transfer to Hospital?

O Yes (1)

O No (2)

Skip To: End of Block If Does the POLST form have a separate section for Future Hospitalization and Transfer to Hospital? = No

Overview 2 What are the options presented under Future Hospitalization / Transfer?

☐ Do not transfer to the hospital (1)

☐ Do not transfer to the hospital unless pain or sever symptoms cannot be otherwise controlled (2)

☐ Transfer to the hospital (3)

☐ Transfer to the hospital, if necessary (4)

End of Block: Overview of POLST form

Start of Block: Overview of POLST form - Intubation

Intubation Q1 Does the POLST form have a separate section for Intubation and Mechanical Ventilation?

O Yes (1)

O No (2)

Skip To: End of Block If Does the POLST form have a separate section for Intubation and Mechanical Ventilation? = No

Intubation Q2 What are the options presented under Intubation and Ventilation section? (Select all that apply)

- ☐ Do not intubate (DNI) (1)
- ☐ Trial period - Intubation and Mechanical ventilation (2)
- ☐ Trial period - Noninvasive ventilation (3)
- ☐ Trial period - Noninvasive ventilation, if health care professional agrees that it is appropriate (4)
- ☐ Intubation and Mechanical ventilation (5)
- ☐ Intubation and long-term mechanical ventilation, if needed (6)
- ☐ Use Noninvasive ventilation (7)
- ☐ Do not use Noninvasive ventilation (8)

End of Block: Overview of POLST form - Intubation

Start of Block: Section 3. Stat's POLST form scan

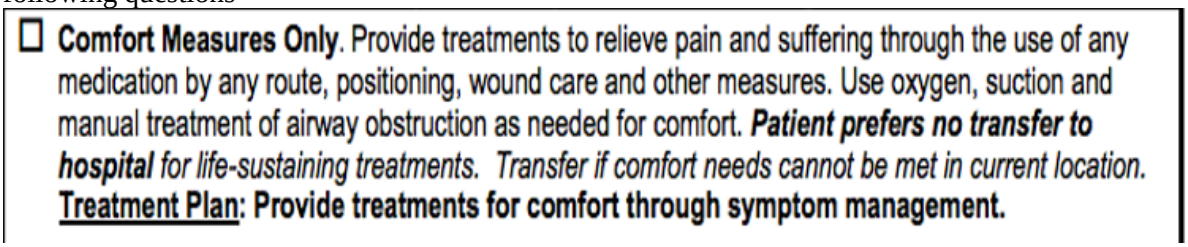
Measures check Does the POLST form include Comfort Measures / Limited Measures / Full Measures section?

- O Yes (1)
- O No (2)

Skip To: End of Block If Does the POLST form include Comfort Measures / Limited Measures / Full Measures section? = No

---

Comfort Measures Please refer to the **“Comfort Measures Only"** section of the graphic below to answer following questions


☐ **Comfort Measures Only**. Provide treatments to relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. ***Patient prefers no transfer to hospital*** *for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.*
Treatment Plan: Provide treatments for comfort through symptom management.

Q18 Is the "Comfort Measures Only" section identical to the example above?

O Yes (1)

O No (2)

Q19 Under the "Comfort Measures Only" section of the state's POLST form, what are the options included? (Select all that apply)

- ☐ Medication (1)
- ☐ Medication by mouth only (2)
- ☐ Medication by any route (3)
- ☐ Positioning (4)
- ☐ Wound Care (5)
- ☐ Oxygen (6)
- ☐ Suction (7)
- ☐ Manual treatment of airway obstruction (8)
- ☐ Antibiotics (9)
- ☐ IV fluids (10)

Q20 Does "Comfort Measures Only" section indicate Transfer / Do not transfer to the hospital?

- O Yes (1)
- O No (2)

Skip To: Limited Treatment If Does "Comfort Measures Only" section indicate Transfer / Do not transfer to the hospital? = No

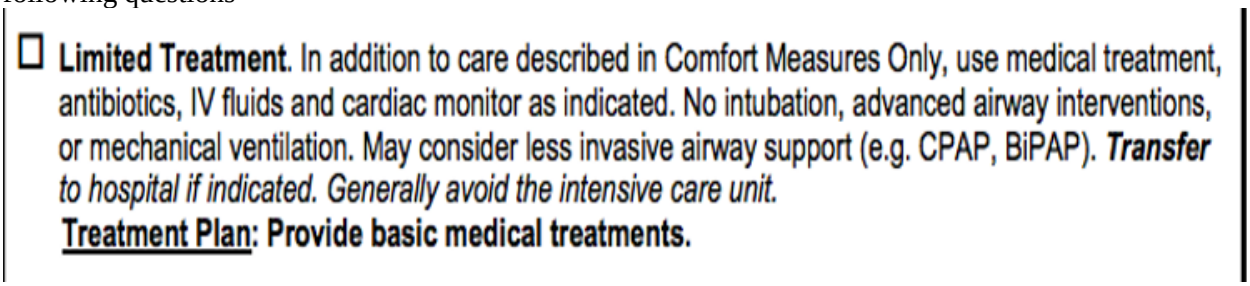
---

Q21 Under Comfort Measures Only, which are the options indicated for patient's hospital transfer? (Select all that apply)

- [ ] "Do not transfer to hospital" (1)
- [ ] "Do not transfer to hospital for life-sustaining treatments" (2)
- [ ] "Transfer only if comfort needs cannot be met in current location" (3)
- [ ] "Patient prefers no transfer to hospital" or "Patient prefers no hospital transfer" (4)
- [ ] "Patient prefers no hospital transfer for life-sustaining treatments" (5)
- [ ] "Avoid calling 911" (6)
- [ ] "If possible, do not transport to ER" (7)
- [ ] "If possible, do not admit to the hospital from ER" (8)

Page Break

Limited Treatment Please refer to the “Limited Treatment" section of the graphic below to answer following questions


☐ **Limited Treatment**. In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). ***Transfer*** *to hospital if indicated. Generally avoid the intensive care unit.*
Treatment Plan: Provide basic medical treatments.

Q22 Is the "Limited Treatment" section identical to the example above?

O Yes (1)

O No (2)

Q23 Under the "Limited Treatment" section of the state's POLST form, what are the options included in addition to the Comfort Measures Interventions? (Select all that apply)

- ☐ IV fluids (1)
- ☐ Cardiac Monitor (2)
- ☐ Antibiotics (PO / IV) (3)
- ☐ Less invasive airway support (CPAP, BiPAP) (4)
- ☐ Intubation, Mechanical Ventilation (5)
- ☐ Medication by mouth (6)
- ☐ Medication through a vein (7)
- ☐ Do not use intubation or mechanical ventilation (8)
- ☐ Interventions aimed at treatment of new or reversible illness / injury /non-threatening chronic condition (9)
- ☐ Not applicable - No options listed (10)
- ☐ Not applicable - options include other interventions such as use of Antibiotics / fluids / nutrition rather than specific activities (11)
- ☐ Oxygen (13)
- ☐ Vasopressor (14)

Q24 Does "Limited Treatment" section indicate Transfer / Do not transfer to the hospital?

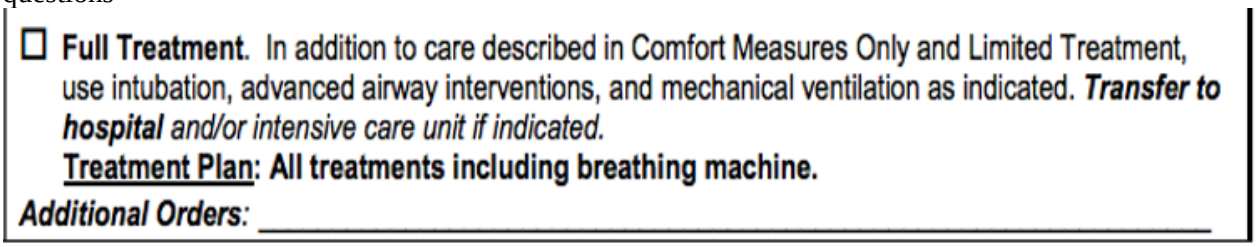
- O Yes (1)
- O No (2)

Q25 Under "Limited Treatment" section, which are the options indicated for patient's hospital transfer?

- [ ] Transfer to hospital if indicated (1)
- [ ] Transfer to hospital if indicated (AND) Avoid intensive care unit (2)
- [ ] Avoid intensive care unit / Generally avoid intensive care unit (3)
- [ ] Transfer to hospital for medical interventions (5)
- [ ] Transfer to hospital only if comfort needs cannot be met in current setting (6)

Page Break

Full Treatment Please refer to the **“Full Treatment"** section of the graphic below to answer following questions


☐ **Full Treatment**. In addition to care described in Comfort Measures Only and Limited Treatment, use intubation, advanced airway interventions, and mechanical ventilation as indicated. ***Transfer to hospital*** *and/or intensive care unit if indicated.*
Treatment Plan: All treatments including breathing machine.
Additional Orders: _____

Q26 Is the "Full Treatment" section identical to the example above?

O Yes (1)

O No (2)

Q27 Under the "Full Treatment" section of the state's POLST form, what are the options included in addition to the Comfort Measures Interventions and Limited Measures Interventions? (Select all that apply)

- [ ] Intubation (1)
- [ ] Advanced airway interventions / Mechanical ventilation (2)
- [ ] Cardioversion (3)
- [ ] Use all medical / surgical intervention (e.g. all treatments) (4)
- [ ] IV fluids (5)
- [ ] No options listed under Full Treatment section (7)
- [ ] All needed treatment / All needed intervention (8)
- [ ] ICU only medication (10)
- [ ] Dialysis (11)

Page Break

Q28 Does "Full Treatment" section indicate Transfer / Do not transfer to the hospital?

- O Yes (1)
- O No (2)

Skip To: End of Block If Does "Full Treatment" section indicate Transfer / Do not transfer to the hospital? = No

Q29 Under "Full Treatment" section, which are the options indicated for patient's hospital transfer? (Select all that apply)

- O Transfer to hospital (1)
- O Transfer to hospital and/or intensive care unit if indicated (2)
- O Transfer to hospital if indicated, including Intensive care unit (3)
- O No options listed under Full Treatment section (4)

Page Break

End of Block: Section 3. Stat's POLST form scan

Start of Block: Use of antibiotics, IV hydration and artificial nutrition

Q30 Is there a separate section in the POLST form which focuses on the utilization of Antibiotics?

- O Yes (1)
- O No (2)

Skip To: Q32 If Is there a separate section in the POLST form which focuses on the utilization of Antibiotics? = No

Q31 What are the options indicated for the use of Antibiotics? (Select all that apply)

- ☐ No antibiotics. Use other measures to relieve symptoms (1)
- ☐ Use antibiotics only to relieve pain and discomfort (2)
- ☐ Determine use or limitation of antibiotics when infection occurs, with comfort as goal (3)
- ☐ Trial period of antibiotics when infection occurs / to treat infection (4)
- ☐ Use antibiotics if medically indicated (5)
- ☐ Use antibiotics if life can be prolonged / to preserve life (6)
- ☐ Antibiotics by IV (7)
- ☐ Antibiotics by PO (8)
- ☐ Antibiotics (9)
- ☐ Use antibiotics consistent with treatment goals (11)
- ☐ Use antibiotics for infection only if comfort cannot be achieved fully through other means (12)

Q32 Is there a section for either artificially administered fluids / hydration OR artificially administered nutrition?

O Yes, there is a section for either artificially administered fluids / hydration OR artificially administered nutrition (1)

O Only Artificially administered fluids / hydration (2)

O Only Artificially administered nutrition (3)

O POLST form does not contain either section (4)

Skip To: Q33 If Is there a section for either artificially administered fluids / hydration OR artificially admini... = Yes, there is a section for either artificially administered fluids / hydration OR artificially administered nutrition

Skip To: End of Block If Is there a section for either artificially administered fluids / hydration OR artificially admini... = POLST form does not contain either section

Skip To: Q34-B If Is there a section for either artificially administered fluids / hydration OR artificially admini... = Only Artificially administered fluids / hydration

Skip To: Q35 If Is there a section for either artificially administered fluids / hydration OR artificially admini... = Only Artificially administered nutrition

Q33 Are there two separate sections for artificially administered fluids / hydration and artificially administered nutrition?

O Yes, there are two separate sections (1)

O No, artificially administered fluids and nutrition options located under ONE section (2)

Skip To: Q34 If Are there two separate sections for artificially administered fluids / hydration and artificially... = Yes, there are two separate sections

Skip To: Q36 If Are there two separate sections for artificially administered fluids / hydration and artificially... = No, artificially administered fluids and nutrition options located under ONE section

Q34 What are the options indicated for the use of artificially administered fluids / hydration? (Select all that apply)

- ☐ No feeding tube (1)
- ☐ No feeding tube, initially (2)
- ☐ No IV fluids (3)
- ☐ No IV fluids, initially (4)
- ☐ Trial period of artificial fluid / hydration via feeding tube (5)
- ☐ Trial period of IV hydration (6)
- ☐ Full / long term fluids / hydration via feeding tube (7)
- ☐ Full / long term IV hydration (8)
- ☐ Other (please specify) (9) _____

Skip To: Q35 If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = No feeding tube

Skip To: Q35 If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = No feeding tube, initially

Skip To: Q35 If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = No IV fluids

Skip To: Q35 If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = No IV fluids, initially

Skip To: Q35 If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = Trial period of artificial fluid / hydration via feeding tube

Skip To: Q35 If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = Trial period of IV hydration

Skip To: Q35 If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = Full / long term fluids / hydration via feeding tube

Skip To: Q35 If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = Full / long term IV hydration

Skip To: Q35 If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = Other (please specify)

Q34-B What are the options indicated for the use of artificially administered fluids / hydration? (Select all that apply)

- ☐ No feeding tube (1)
- ☐ No feeding tube, initially (3)
- ☐ No IV fluids (4)
- ☐ No IV fluids, initially (5)
- ☐ Trial period of artificial fluid / hydration via feeding tube (7)
- ☐ Trial period of IV hydration (8)
- ☐ Full / long term fluids / hydration via feeding tube (9)
- ☐ Full / long term IV hydration (10)
- ☐ Other (please specify) (11) _____

Skip To: End of Block If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = No feeding tube

Skip To: End of Block If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = No feeding tube, initially

Skip To: End of Block If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = No IV fluids

Skip To: End of Block If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = No IV fluids, initially

Skip To: End of Block If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = Trial period of artificial fluid / hydration via feeding tube

Skip To: End of Block If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = Trial period of IV hydration

Skip To: End of Block If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = Full / long term fluids / hydration via feeding tube

Skip To: End of Block If What are the options indicated for the use of artificially administered fluids / hydration? (Sele... = Full / long term IV hydration

Skip To: End of Block If What are the options indicated for the use of artificially administered fluids / hydration? (Sele...(Other (please specify)) Is Not Empty

Q35 What are the options indicated for the use of artificially administered nutrition? (Select all that apply)

- [ ] No tube feeding / No artificial nutrition, including tube feeding (1)
- [ ] No tube feeding - Initially (2)
- [ ] Defined trial / short term period of artificial nutrition by feeding tube (3)
- [ ] Long-term / permanent artificial nutrition by tube (4)
- [ ] Artificial nutrition, unless it provides no benefit (5)
- [ ] No TPN (6)
- [ ] No TPN - Initially (7)
- [ ] TPN for a trial period (8)
- [ ] TPN long-term (9)

Skip To: End of Block If What are the options indicated for the use of artificially administered nutrition? (Select all th... = No tube feeding / No artificial nutrition, including tube feeding

Skip To: End of Block If What are the options indicated for the use of artificially administered nutrition? (Select all th... = No tube feeding - Initially

Skip To: End of Block If What are the options indicated for the use of artificially administered nutrition? (Select all th... = Defined trial / short term period of artificial nutrition by feeding tube

Skip To: End of Block If What are the options indicated for the use of artificially administered nutrition? (Select all th... = Long-term / permanent artificial nutrition by tube

Q36 What are the options under artificially administered fluids AND nutrition?

- [ ] No feeding tube (e.g. No artificial nutrition or hydration by tube) (1)
- [ ] No IV fluids (2)
- [ ] A trial period of feeding tube (either hydration or nutrition) (11)
- [ ] A trial period of IV fluids (3)
- [ ] Artificial nutrition and hydration (with no indication for period) (12)
- [ ] Long term feeding tube (fluids, artificial nutrition by tube) (4)
- [ ] Long term IV fluids (13)

Page Break

End of Block: Use of antibiotics, IV hydration and artificial nutrition

Start of Block: Signing of the POLST form

Q37 Clinicians authorized to sign the form (select all that apply)

- ☐ Medical Doctor (M.D) (1)
- ☐ Doctor of Osteopathic Medicine (D.O) (2)
- ☐ Advanced Practice Registered Nurse (APRN) / Nurse Practitioner (NP) (3)
- ☐ Physician Assistant (P.A) (4)
- ☐ "Licensed provider" (specific titles not provided) (5)
- ☐ Licensed resident (6)
- ☐ Licensed resident (second year or higher) (7)
- ☐ Clinical Nurse Specialist (CNS) (8)

Comment section

_____

End of Block: Signing of the POLST form

Appendix B. Newcastle-Ottawa Quality Assessment Tool

NEWCASTLE - OTTAWA QUALITY ASSESSMENT SCALE
CASE CONTROL STUDIES

Note: A study can be awarded a maximum of one star for each numbered item within the Selection and Exposure categories. A maximum of two stars can be given for Comparability.

Selection

1) Is the case definition adequate?
   a) yes, with independent validation ✸
   b) yes, eg record linkage or based on self reports
   c) no description

2) Representativeness of the cases
   a) consecutive or obviously representative series of cases ✸
   b) potential for selection biases or not stated

3) Selection of Controls
   a) community controls ✸
   b) hospital controls
   c) no description

4) Definition of Controls
   a) no history of disease (endpoint) ✸
   b) no description of source

Comparability

1) Comparability of cases and controls on the basis of the design or analysis
   a) study controls for _____ (Select the most important factor.) ✸
   b) study controls for any additional factor ✸ (This criteria could be modified to indicate specific control for a second important factor.)

Exposure

1) Ascertainment of exposure
   a) secure record (eg surgical records) ✸
   b) structured interview where blind to case/control status ✸
   c) interview not blinded to case/control status
   d) written self report or medical record only
   e) no description

2) Same method of ascertainment for cases and controls
   a) yes ✸
   b) no

3) Non-Response rate
   a) same rate for both groups ✸
   b) non respondents described
   c) rate different and no designation

NEWCASTLE - OTTAWA QUALITY ASSESSMENT SCALE
COHORT STUDIES

Note: A study can be awarded a maximum of one star for each numbered item within the Selection and Outcome categories. A maximum of two stars can be given for Comparability

Selection

1) Representativeness of the exposed cohort
   a) truly representative of the average _____ (describe) in the community ✸
   b) somewhat representative of the average _____ in the community ✸
   c) selected group of users eg nurses, volunteers
   d) no description of the derivation of the cohort

2) Selection of the non exposed cohort
   a) drawn from the same community as the exposed cohort ✸
   b) drawn from a different source
   c) no description of the derivation of the non exposed cohort

3) Ascertainment of exposure
   a) secure record (eg surgical records) ✸
   b) structured interview ✸
   c) written self report
   d) no description

4) Demonstration that outcome of interest was not present at start of study
   a) yes ✸
   b) no

Comparability

1) Comparability of cohorts on the basis of the design or analysis
   a) study controls for _____ (select the most important factor) ✸
   b) study controls for any additional factor ✸ (This criteria could be modified to indicate specific control for a second important factor.)

Outcome

1) Assessment of outcome
   a) independent blind assessment ✸
   b) record linkage ✸
   c) self report
   d) no description

2) Was follow-up long enough for outcomes to occur
   a) yes (select an adequate follow up period for outcome of interest) ✸
   b) no

3) Adequacy of follow up of cohorts
   a) complete follow up - all subjects accounted for ✸
   b) subjects lost to follow up unlikely to introduce bias - small number lost - > ____ % (select an adequate %) follow up, or description provided of those lost) ✸
   c) follow up rate < ____% (select an adequate %) and no description of those lost
   d) no statement

Appendix C. Physician Orders for Life-Sustaining Treatment (POLST) Sample Form

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 4/1/2017)*

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: *(optional)*

A — CARDIOPULMONARY RESUSCITATION (CPR): *If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.*

Check One

☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A **requires** selecting Full Treatment in Section B)

☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

B — MEDICAL INTERVENTIONS: *If patient is found with a pulse and/or is breathing.*

Check One

☐ **Full Treatment – primary goal of prolonging life by all medically effective means.**
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.

☐ ***Trial Period of Full Treatment.***

☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.**
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

☐ ***Request transfer to hospital only if comfort needs cannot be met in current location.***

☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.**
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Additional Orders: _____

_____

C — ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible and desired.*

Check One

☐ Long-term artificial nutrition, including feeding tubes. Additional Orders: _____

☐ Trial period of artificial nutrition, including feeding tubes. _____

☐ No artificial means of nutrition, including feeding tubes. _____

D — INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _____, available and reviewed →
☐ Advance Directive not available
☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: _____
Phone: _____

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
Physician/NP/PA Signature: *(required)*		Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name:		Relationship: *(write self if patient)*
Signature: *(required)*	Date:	Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011, 10/1/2014 or 01/01/2016 are also valid

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Patient Information

Name (last, first, middle):	Date of Birth:	Gender: M F

NP/PA's Supervising Physician	**Preparer Name** (if other than signing Physician/NP/PA)	
Name:	Name/Title:	Phone #:

Additional Contact ☐ None

Name:	Relationship to Patient:	Phone #:

Directions for Health Care Provider

Completing POLST

- **Completing a POLST form is voluntary**. California law requires that a POLST form be followed by healthcare providers, and provides immunity to those who comply in good faith. In the hospital setting, a patient will be assessed by a physician, or a nurse practitioner (NP) or a physician assistant (PA) acting under the supervision of the physician, who will issue appropriate orders that are consistent with the patient's preferences.
- **POLST does not replace the Advance Directive**. When available, review the Advance Directive and POLST form to ensure consistency, and update forms appropriately to resolve any conflicts.
- POLST must be completed by a health care provider based on patient preferences and medical indications.
- A legally recognized decisionmaker may include a court-appointed conservator or guardian, agent designated in an Advance Directive, orally designated surrogate, spouse, registered domestic partner, parent of a minor, closest available relative, or person whom the patient's physician/NP/PA believes best knows what is in the patient's best interest and will make decisions in accordance with the patient's expressed wishes and values to the extent known.
- A legally recognized decisionmaker may execute the POLST form only if the patient lacks capacity or has designated that the decisionmaker's authority is effective immediately.
- To be valid a POLST form must be signed by (1) a physician, or by a nurse practitioner or a physician assistant acting under the supervision of a physician and within the scope of practice authorized by law and (2) the patient or decisionmaker. Verbal orders are acceptable with follow-up signature by physician/NP/PA in accordance with facility/community policy.
- If a translated form is used with patient or decisionmaker, attach it to the signed English POLST form.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid. A copy should be retained in patient's medical record, on Ultra Pink paper when possible.

Using POLST

- Any incomplete section of POLST implies full treatment for that section.

Section A:

- If found pulseless and not breathing, no defibrillator (including automated external defibrillators) or chest compressions should be used on a patient who has chosen "Do Not Attempt Resuscitation."

Section B:

- When comfort cannot be achieved in the current setting, the patient, including someone with "Comfort-Focused Treatment," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), bi-level positive airway pressure (BiPAP), and bag valve mask (BVM) assisted respirations.
- IV antibiotics and hydration generally are not "Comfort-Focused Treatment."
- Treatment of dehydration prolongs life. If a patient desires IV fluids, indicate "Selective Treatment" or "Full Treatment."
- Depending on local EMS protocol, "Additional Orders" written in Section B may not be implemented by EMS personnel.

Reviewing POLST

It is recommended that POLST be reviewed periodically. Review is recommended when:

- The patient is transferred from one care setting or care level to another, or
- There is a substantial change in the patient's health status, or
- The patient's treatment preferences change.

Modifying and Voiding POLST

- A patient with capacity can, at any time, request alternative treatment or revoke a POLST by any means that indicates intent to revoke. It is recommended that revocation be documented by drawing a line through Sections A through D, writing "VOID" in large letters, and signing and dating this line.
- A legally recognized decisionmaker may request to modify the orders, in collaboration with the physician/NP/PA, based on the known desires of the patient or, if unknown, the patient's best interests.

This form is approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST Task Force.
For more information or a copy of the form, visit **www.caPOLST.org**.

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED